

# **Childhood Acquired Brain Injury: An Exploratory Study into the Educational Experiences of Children, Their Families and the Professionals who Support Them.**

Submitted by Victoria Wright, to the University of Exeter as a thesis for the degree of Doctor of Educational Psychology in Educational, Child and Community Psychology, March 2014.

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I certify that all material in this thesis which is not my own work has been identified and that no material has been submitted and approved for the award of a degree by this or any other University.

Signed: .....

Victoria Wright

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“Arrange whatever pieces come your way”.

-Virginia Woolf

## Overview of Thesis

Acquired Brain Injury (ABI) can result in significant and long lasting additional needs for children, their families and the professionals tasked with supporting them (Middleton, 2001b; Walker & Wicks, 2005). This paper reports the two parts of a small scale study, the aim of which was to illuminate the factors (areas of good practice, issues & challenges) involved in educating children after ABI. The first paper explores the views and experiences of children and young people<sup>1</sup> with ABI and their parents. It identifies how children describe their experiences of school since injury, their parent's experience of the injury and schooling thereafter, as well as what areas of need exist in terms of improvement in support for this group of children and young people.

The second part explores the views and experiences of school based practitioners as well as professionals from a range of external agencies that work with children, young people, their families and schools. The main aims were to stimulate discussion of what roles school staff and external agency professionals have in supporting children with ABI, the ways in which they work together and with children, young people and families and what, if any, improvements were thought to be important.

Together, both parts of this research seek to illuminate pertinent factors for those involved, in order to inform future practice for Educational Psychologists (EPs) and the professionals they work with in schools and external agencies.

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<sup>1</sup> The terms 'children' and 'young people' will be used interchangeably in this paper to describe all people aged between 0 and 18 years of age.

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## **Paper One**

### **The Views and Experiences of Children and Young People with ABI and Their Parents**

## 1 Abstract Paper One

The aim of this paper was to generate new understanding with regard to the experiences of children and young people who have experienced ABI and their parents, particularly with regard to education since the injury. Semi-structured interviews were used to gather the views of children (N=6) and parents (N=5) about the experience of having an ABI, the effect of this on others and the characteristics of the support they have received since injury. Interviews were transcribed and a thematic analysis approach was adopted to analyse the data gathered. Interview responses were organised into themes which represented a variety of information, ranging from a first-hand account of ABI, experiences of the support received from schools and external agency professionals and the various impacts of an ABI. It was found that overall, all participants described a positive experience in terms of support they had received since ABI although this rested largely on others having adequate knowledge. In addition to this, it was revealed how children and young people have experienced ABI, ranging from changes in self-concept and peer relationships to fatigue and the expectations in a school environment for academic achievement. It was felt that the communication skills of professionals, improved knowledge and awareness of ABI and support over time for children and families would be important areas of focus for the future.

## 2 Introduction

### 2.1 Purpose

This is the first of two papers exploring experiences associated with childhood ABI from the perspectives of children and young people who have ABI and their parents. The purpose is to generate new understandings in relation to the lived experiences of children and young people with ABI, how they and their parents describe the support from schools and external agency professionals since ABI and what could be done to improve that support.

### 2.2 Terms of Definition

It is important to consider what is meant by ABI because sometimes the terms ABI and traumatic brain injury (TBI) are used interchangeably in the literature (Bozic & Morris, 2005). It is necessary to outline the definition of ABI as used in this research and other literature in the field. ABI has been described as including any injury that has occurred to the brain after birth that is non-progressive (Rehab Group UK, 2010). It can be caused by external force, such as a fall or accident (traumatic), or by illness such as meningitis, tumours and haemorrhage (non-traumatic) (Walker & Wicks, 2005; Cassidy, 2009). More detailed definition and causes of ABI can be seen in appendix A.

Unlike other Special Educational Needs (SEN), ABI has been described as presenting a unique set of characteristics which can prove to be challenging for schools because they are so often unrecognised (Walker & Wicks, 2005; Walker, 2009). The distinct differences between children with ABI and those with other SEN are crucially linked to the process of learning. This is impacted to a differing extent depending on the cause of the injury, areas of the brain damaged and the child or young person's previous learning styles. Some of the



characteristics that make ABI unique from other SEN include: the unpredictable consequences on the immature and developing brain; a discrepancy in learning skills due to a period of typical development and growth prior to injury; and the emotional stress for the injured person and their family. It is important for school staff and other professionals to understand and acknowledge these unique characteristics so as to ensure that appropriate strategies of support are implemented in the educational setting (Walker & Wicks, 2005).

### 2.3 Context

ABI has been described as a common cause of acquired disability (Anderson, Brown, Newitt & Hoile, 2011) and as a “critical public health problem worldwide” (Hyder, Wunderlich, Puvanachandra, Gururaj & Kobusingye, 2009, p. 341). The means by which a person can be affected by ABI span a variety of areas of functioning including those that may not be visible at the physical level. As such ABI has been described as a hidden disability (Sharp, Bye, Llewellyn & Cusick, 2006).

Outcomes and effects following ABI are wide and varied, can become more apparent over time and can range from an almost complete recovery to significant and long lasting disability (Byard, Fine & Reed, 2011; Middleton, 2001a; McCusker, 2005). The effect on functioning across the physical, cognitive, behavioural, social and emotional domains can impact greatly on a child’s learning and development as well as the people who support them (Byard et al., 2011; Glang, Todis, Thomas, Hood, Bedell & Cockrell, 2008).

Whilst there is not agreement within the literature with regard to the statistics around childhood ABI, there have been some attempts to estimate the number of individuals affected by United Kingdom (UK) based researchers. Hawley, Ward, Long, Owen and

Magnay (2003) estimated that in a Northern UK region, 280 per 100,000 children experience a 24 hour or more stay in hospital because of a brain injury. Moderate or severe injury accounted for 15% of these admissions. This data is useful in terms of developing knowledge and understanding about the number of children affected by ABI and to what extent. However, it appears that this is a gap in literature around childhood ABI because by being based only on a single region within the UK, data from a wider geographical spread is missing.

Obtaining data about the numbers of ABI within the local authority that this research was conducted proved difficult. Through interviews and correspondence with some of the professionals based in the health service I was able to ascertain that during one month in the Summer 2012, there were 8 young people admitted to the local hospital Accident and Emergency (A&E) department due to a brain injury. Clearly this figure only represents those who presented at A&E and does not include those who did not, or those already on a hospital ward due to illness or infection. Existing literature has highlighted that accurate statistical information on the prevalence of ABI in children is difficult to obtain (Walker & Wicks, 2005) and this appears to be to be an issue in this area.

This paper will have a qualitative focus with the aim of gaining a rich picture of the views of children and young people and their parents to develop understanding about how it is experienced. As shall be discussed in the next section, the voices of those affected by ABI have been largely overlooked in the research thus far. The lack of research including the lived experiences of ABI as well as my own interest and work experience in this area was the motivation for conducting this piece of work. Please see appendix B for further details of

my perspective as researcher and appendix C for a summary of the learning opportunities I have pursued during the research period.

### 3 A Review of Literature

This section includes a discussion of literature relevant to parents and children and young people affected by ABI. A detailed literature review has formed the basis for this research and can be found in appendix D. Details are given within that review of how the search for literature was conducted.

#### 3.1 Views of Parents

Parents of children with ABI feature in the literature to a certain extent and often from a particular focus. For example, a families' reactions to and needs following ABI has been discussed and measured through the use of questionnaires in literature from Canada (Armstrong & Kerns, 2002) and America (Aitken et al., 2009).

Armstrong and Kerns (2002) found that when comparing the experiences of parents of children with ABI to parents of children with orthopaedic injuries and diabetes, parents of children with ABI reported a greater number of additional needs across a number of areas. These included the need for health related information and community support networks following their child's injury and these needs remained unmet in the majority of cases.

Similarly, through the use of questionnaires and rating scales, Aitken et al. (2009) found that the caregivers of children with ABI reported an additional burden when their child was in poor health and they had needs which were unmet. In relation to stress and worry following the child's ABI, it was found that caregivers reported worry and concerns about the child's physical functioning, emotional health, learning skills as well as financial difficulties for the whole family.

There is concurrence between these researchers; that families experience stress and on-going concerns associated with ABI, from worry about children's skills and functioning across different areas to concern about finances and a need for information over time.

However, what is not known from existing literature is how parents have experienced schooling for their child since ABI, their experiences with school and external agency professionals and what they would like to see improved upon within an educational context. Secondly, no studies similar to those discussed above have been identified from the UK indicating that this is a gap in literature relevant to children and young people affected by ABI and their parents in this country.

### 3.2 Views of Children

It has been recognised within the literature that there is very little research including accounts of ABI from those directly affected (Crisp, 1993). Research specific to the experiences of children is limited and whilst the views of adults have been sought (Crisp), literature has more often reported on data of a quantitative nature and not included the opinions and experiences of children directly affected (Boylan, Linden & Alderdice, 2009). Only one study has been identified that includes the views of young people with ABI and this will be discussed in more detail below.

Exploring the views of adolescents who had experienced severe ABI in Australia was the aim of Sharp et al. (2006). Using a grounded theory approach to analyse data collected from interviews, Sharp et al. concluded the main challenge for the adolescents was fitting back in on their return to school. Factors involved in the success of a return to school included the organisation of the return itself and the support they received from teachers and their

parents. What was positive about this study is that it was longitudinal in nature with interviews with adolescents and their families occurring over a two year period. Research similar to this from the UK has not been identified and as such this is currently a gap in the literature. Research pertaining to the UK education system and support services available to children and their families, along with the views of younger children would be a useful addition to this existing study. Indeed, Sharp et al. identified that further research into the perspectives of those affected by ABI, their peers and teachers would be a useful addition to their work.

In addition to this, sources have been identified that have included the perspective of those directly affected by ABI (Calderwood, 2003; Child Brain Injury Trust [CBIT], 2003; Fairclough, 2002). However, these have been done for specific purposes, not published as research and are arguably limited in their perspective and the inclusion of the views of others (for example, parents).

To summarise, there is agreement in the existing literature that not enough is known about how children experience their ABI. It is possible that the challenges involved in having child participants, especially those who may have difficulty thinking or communicating due to ABI have led to this being an under researched area. Indeed, researchers have recognised and written about the potentially complex issues and considerations needed before planning to include children affected by ABI in research (Boylan et al., 2009; Carlsson, Paterson, Scott-Findlay, Ehnfors & Ehrenberg, 2007). Given the lack of existing literature in this area, it is arguable that the potential benefit outweighs the challenges. As such, consideration of factors relevant to conducting interviews with children and young people living with the effects of ABI are discussed in the methodology section.

### 3.3 Theoretical Perspective

Ecological Systems Theory (Bronfenbrenner, 1979) highlights the importance of interactions between systems when attempting to understand human development. Due to the wide ranging effects of ABI including the worry and stress reported by parents (Aitken et al., 2009), consideration of factors from across the different contexts a child functions within is important, as is exploration of views from multiple groups. According to Bronfenbrenner, the ecological environment encompasses the developing child, the environment and the interaction between the two. As such, Ecological Systems Theory will be used to frame this paper because as discussed above, the impact of ABI stretches beyond the child or young person. The focus of this paper is the microsystem.

## 4 Research Aim

To summarise, ABI is an under researched area, especially in terms of including the views and experiences of those directly affected and yet what is clear from existing research is that the consequences of ABI can be long-lasting, wide ranging and changing. As a result of the gaps highlighted by this literature review, the general aim of this paper is to explore the views and experiences of children and young people with ABI and their parents with a view to developing understanding of how ABI and education after the injury is experienced.

In detail, this includes the following research questions:

1. How does a child who has experienced ABI describe their experiences of school since the injury?
2. What is the perspective of parents of children with ABI with regard to their child's schooling experience since the injury?
3. What are the perceived improvements that could be made in the future in relation to the schooling experience for children with ABI?



## 5 Methodology

### 5.1 Research Design

As the views of children and young people and their parents are central to this study, a flexible research design consistent with an interpretive approach and social constructionist philosophy was used. According to Creswell (2008), the goal of the constructionist researcher is to focus on the participants' views of the situation being studied (ABI), consider interactions among individuals (who and what have been supportive or challenging) and focus on specific contexts (school). As researcher, I have acknowledged that my previous training and life experiences are part of the data collection and analysis (Wilkinson, Joffe & Yardley, 2004). It was necessary to consider how this affected my performance as researcher. Please see appendix B for a discussion of my previous work experience in the area of ABI and my reflections upon this.

This research can be described as one of qualitative inquiry (Robson, 2011). It has been suggested that a qualitative approach is especially suitable for research with children (Greig, Taylor & MacKay, 2007). Given that a significant gap in existing literature is the voice of children and young people, qualitative data collection allowed this to be captured in more detail and depth than quantitative data may have done. It has been suggested that qualitative data strives for depth of understanding in natural settings and allows detailed exploration (Greig et al., 2007).

In terms of methodology, illuminative enquiry, which aims to describe and interpret (Parlett & Hamilton, 1972) was used. According to Burden (1998), illuminative enquiry or evaluation seeks to explore and discover situations and the experiences of the participants. Rather

than producing a set of results that could be exactly replicated in another context with different participants or a different researcher, the current study aimed to make sense of the experiences of those people who took part. However, exploring the experiences of the current participants could result in interesting insights for working with similar participants in the future, both in research and practical capacities (Wilkinson, Joffe & Yardley, 2004).

## 5.2 Participants

The research took place in a local authority within the South West of England; there were a total of 11 participants (six children & five parents; see appendix E for more details). It was hoped that there would be an even number of matched pairs in terms of parents and their children. However, one parent did not wish to be interviewed with their child independently responding to information their parents had been given about the research. An opportunistic sampling technique was used in which new participants were recruited as the research went on. By writing to schools, liaising with Educational Psychology colleagues, attending a support group for parents of children with ABI and liaising with the Specialist Paediatric Occupational Therapist (OT), I was able to recruit all of the participants. Doing this meant that young people not known to the Educational Psychology Service could also be identified. In terms of who was included in the research, sampling was flexible because I did not want to rule anyone out with a strict set of criteria, especially because this is an under researched area. Therefore, the only conditions for a child's participation were: to live and go to school within the local authority, attend a mainstream school and be under 18 at the time of interview. All participants were known to the Specialist Paediatric OT.

The main difficulty in participant recruitment was identification. No official database of children known to education services with ABI exists. The Educational Psychology Service

receives a letter from the local hospital after a child has presented with ABI so as to inform the service that the child may experience difficulties related to ABI at school. However, this is only with parental consent and does not include consent for their details to be used for other purposes (such as research). In addition to this, none of the information is stored electronically and searching through this would be an inefficient use of time. Once identified and approached, participants agreed to take part (apart from the one parent discussed above) and none have withdrawn their consent.

### 5.3 Data Collection

Semi-structured interview schedules (appendix F) were devised using hierarchical focusing (Tomlinson, 1989) and covered similar topics for children and their parents. I used existing literature to help define which aspects of the topic views would be explored. My concern was to uncover the authentic views of participants whilst avoiding influencing their responses; hierarchical focusing was the technique used to achieve this and my reflections and discussion of themes from existing literature in appendix F show how this was done. The interviews were discussed with both academic and EP supervisors. Two pilot interviews were conducted, one for each interview schedule. Slight adjustment was made to the wording of two questions (see appendix F). Carrying out these interviews also allowed preparation and later reflection on the process of interviewing with an EP supervisor. The data from the pilot interviews has been included in the overall analysis due to the small sample size, the minor changes to the questions and the unique and interesting views and experiences of the participants.

Semi-structured interviews were chosen because of the flexibility they offer in being able to have a list of areas to explore whilst having freedom in the timing, exact wording and

sequencing of questions (Robson, 2011). Indeed, Wilkinson, Joffe and Yardley (2004) highlight the advantages of open-ended questions which allow for each person's own words and reactions to be expressed rather than a response to a set of predefined questions as would be the case with a questionnaire for example. Whilst I considered other data collection methods such as focus groups, these were discounted because of the sensitive nature of the topic and the issues of confidentiality with focus groups (Wilkinson, Joffe & Yardley). Semi-structured interviews on the other hand are especially suitable for those researchers interested in complex processes and where the issues being discussed are personal, as is the case with ABI (Smith, 1995). It was important for participants to be interviewed in a way in which they felt most comfortable to share stories that are laden with a variety of emotions, memories and sensitive information (both about the participants themselves and the people who have supported them).

Interviews took place between July and December 2012 at a location convenient for the participants. For flexibility and to maximise conditions in which participants would feel comfortable, parents and children were given the choice of whether to be interviewed at home, in school, their own place of work or an EP office. All participants chose to be interviewed at school or in their own homes. When interviews were conducted in the homes of participants, the local lone working policy was followed.

Parents were present at their child's interview in 5 out of the 6 cases. Irwin and Johnson (2005) suggested that mediation from parents can support the richness of an account and provoke shared memories. Due to the potential effects of ABI and the differing extents to which children were able to remember events, it was decided that the presence of parents at interviews would be useful.

I digitally recorded, transcribed and read all of the interviews (see appendix G for example transcripts).

#### 5.4 Data Analysis

Data was analysed using thematic analysis which is a flexible way to identify themes within data (Braun & Clarke, 2006). An inductive approach was used, the codes and themes were data driven (see appendix H for further details of the analysis). This was considered suitable in what is a relatively under explored topic in terms of research (especially in the context of education) and therefore no framework exists to which the data could be coded. The thematic analysis approach was chosen so I could look for commonality across the interviews.

The data from children and parents were coded separately and then these codes were combined as many were similar and were telling the same stories. It was also decided that this would add another layer in terms of protecting participant anonymity rather than exploring themes for each person. Too much detail about individual stories may otherwise have been identifiable. Whilst time constraints did not allow for inter-rater reliability on this occasion, the individual stories from participant interviews and themes as the analysis progressed were discussed and reflected upon with EP and academic supervisors.

## 5.5 Preparation and Ethical Considerations

In preparation for data collection, approval from the University of Exeter's Ethics Committee was sought and obtained (see appendix I) and reading of relevant papers was undertaken to consider the pertinent issues in interviewing children and young people in particular.

Informed consent was sought from the children's parents for them to take part. An information sheet was provided to the parents and children for consideration prior to the interview. At the start of the interviews, all participants, especially the children and young people were briefed again about the research aims and assured that they could withdraw at any time. It was also important to gain assent from the children for their participation (see appendix J for all consent documents). Assent has been described as the child's agreement to take part in the process when someone else has given consent on their behalf (Lewis, 2002). To do this, the children were asked to write their name and circle a smiley (yes) or sad (no) face as a means of agreeing or disagreeing to take part. Cocks (2006) recommended that gaining assent from a child to take part in research is an on-going process and the researcher needs to remain aware of how the child responds and communicates. Given my educational psychology training, I felt that this was something I was skilled in.

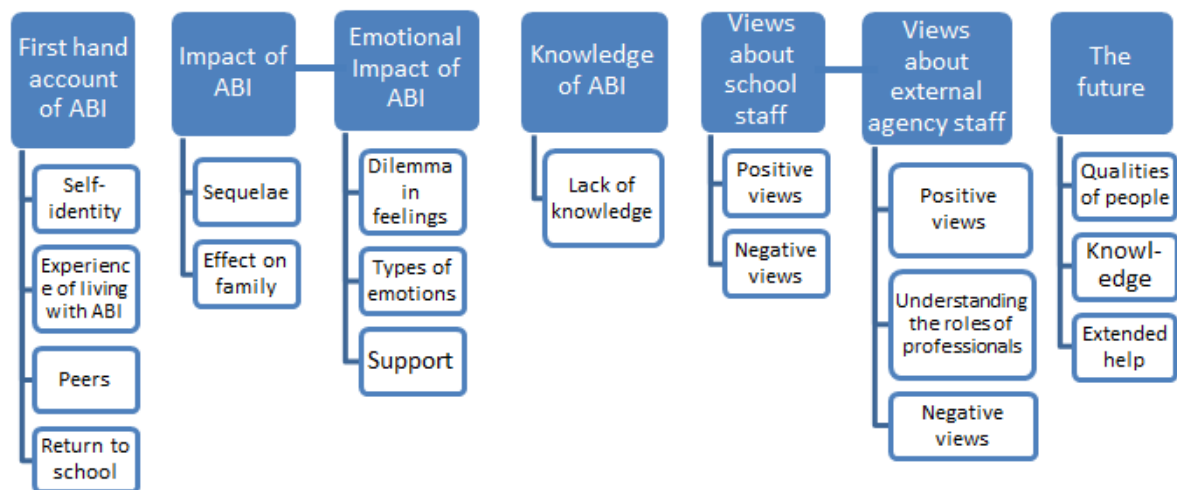
All names have been changed throughout this research. Additionally, in some interview transcripts people talked about by participants have been referred to as 'they' or 'them' to further protect identities, especially with regard to groups of particular professionals and/or schools in the local authority.

Finally, consideration was given to the difficulties which may be experienced by some children and young people in communicating their thoughts and opinions due to their ABI. Whilst other researchers (Child Brain Injury Trust, 2003; Lewis, 2002) have discussed using pictures, it is again an under researched area with little to replicate in terms of supportive communication tools. In light of this, symbols from the Makaton language programme (The Makaton Charity, 2014) were selected that were relevant to the topic of the interviews (for example, 'school', 'teacher') along with more general words such as 'yes' and 'no'. The symbols were taken to each interview and available although all participants chose to talk freely. Whilst some found this harder than others, I respected their choice to talk and felt I had to act cautiously so as not to patronise the children and young people or make them feel uncomfortable.

## 6 Findings

“It is gonna change you and it is gonna change who you are but if you can remember who you were before you can kind of incorporate the two together.” (Beth, Child on ABI)

This section will discuss the themes that were created as a result of the thematic analysis of the interview data with the 11 participants. A descriptive exploration of each theme that emerged will be presented in relation to the research questions. Due to parents and young people being interviewed in the presence of each other (see section 5.3) and codes being combined for the analysis, most themes will be presented under research questions one and two to show the links between them (see appendix K for additional quotes).



### 6.1 Research Questions One and Two

Question one: How does a child who has experienced ABI describe their experiences of school since the injury?

Question two: What are the views of parents of children with ABI with regard to their child’s schooling experience since the injury?



### 6.1.1 Theme One: First Hand Account of ABI

The children and young people were willing and able to share a number of advisory points about their experience of ABI. Typical points included: feelings of loneliness, frustrations around being able to effectively share their concerns and difficulties with others and others recognising that they still exist as the same person despite ABI. The four subthemes below explore these general points in more detail.

#### **Self-identity**

An aspect that was evident in children and young people's talk about the experience of having ABI was their self-identify. Age appeared to be a factor in the young people's ability to reflect on the experience of living with brain injury and the level of detail given. The older children talked about their independence and differing levels of this since injury; for example, travelling to school independently with peers when they were able to.

Needing to adjust their view and expectations of themselves as well as coping with and developing an understanding of the effects of ABI was also an important factor in this aspect of the first-hand account of ABI. The older children were also able to reflect on how they must appear differently to people who know them well and therefore how their injury affects others.

"To start with it was just a big deal to say I've got a brain injury and then it was a big deal to say it means that I've got memory problems and then slowly I've become more comfortable with talking about it so...it's a long process." (Beth, Child)

"I mean I wasn't gonna just be the original Mike or I'd be in sixth form now and we wouldn't be having this conversation." (Mike, Child)

## **Experience of Living with ABI**

Difficulty in forming a routine again after ABI, particularly with regard to schoolwork was highlighted as an issue by children and young people. Linked to this was the impact of fatigue and the task of getting out of bed and getting to school. Children were able to describe emotions and feelings they had experienced, for example, pain, happiness and misery. In addition to this, memory issues related to fatigue and how this affected their behaviour towards others, for example, the ability to engage in conversation and snapping at people was discussed. Most children talked particularly about how they could not remember the incident causing ABI to the point that they described it as something that happened to the rest of their family rather than them.

“It took a while getting used to doing work again.” (Billy, Child)

“When I came back to school, I did need a lot of help.” (Jack, Child)

“I just didn’t work it was just quite impossible because I just couldn’t, it’s like my head just wouldn’t click on to what was going on.” (Cassie Child)

## **Peers**

Two of the young people (the only girls in the cohort) described feeling misunderstood by peers, including people they classed as friends prior to the ABI. The two girls described their relationships in greater detail than the boys. The narratives were richer and they talked about feeling excluded from their existing friendship groups upon their return to school. In contrast, all of the boys reported ease with regard to returning to school and being accepted by their friends, but described their relationships in less detail than the girls. They

reported keeping the same friendship groups, being pleased to see their friends again and had less concerns about integrating back into existing groups.

The girls tended to align themselves more with other children who had experienced stress or had their own needs, for example, SEN, mental health needs or the experience of a parent dying. Both girls described making new friends with other young people who they perceived to be similar to them. They described being able to relate to these other young people because they all had to *“kind of grow up and realise that life’s not always that fair but actually you can really enjoy it”* (Beth Child).

“Like when you tell people that you’ve got a brain injury obviously they freak out.”  
(Beth Child)

“Yeah um, I made some friends before I got run over erm, and they’re still my friends today which is good coz they’ve understood me mostly.” (Mike Child)

“I think it was that people didn’t understand me, people like my friends for instances.” (Cassie Child)

### **Return to School**

Positive experiences at school after ABI outweighed negative experiences in the children’s opinions. Children described feelings of happiness, and excitement about going back. Most felt that they were doing well in school and making progress and parents concurred with this. One young person did not have a successful secondary school experience after ABI and as such moved to a pupil referral unit (PRU) which then made for a more positive educational experience.

“I just felt just really, I, it wasn’t actually quite different I just treated that day as a normal day.” (Jack Child)

“It’s going good – I: yeah – um, I feel like I’m making progress a bit and um, I’m making new friends almost every day – I: ok – it’s getting a lot easier sometimes, in certain lessons.” (Owen Child)

### 6.1.2 Theme Two: Impact of ABI

#### **Sequelae**

All participants were able to describe the difficulties that were faced by the children and young people following the ABI. A range of effects were reported by parents and young people ranging from physical effects such as headaches, problems with vision and fatigue to a range of emotional and behavioural effects such as disruptive behaviour, anger, frustration and self-destructive behaviour.

On-going physical effects such as nosebleeds and headaches were linked to a level of distress for parents and the young people. Tiredness and fatigue was also a common issue highlighted by participants that led to frustration. Children and young people in particular noted a difference in their energy and levels of tiredness after ABI and discussed how they were not themselves when tired and of little use to others, for example, in terms of having a coherent conversation with others. They also described fatigue in terms of their brain stopping working and their body aching intensely.

The hidden effects of ABI were particularly described in terms of subtle personality changes and memory difficulties. One parent described their child as seeming out of character since the ABI, but was not able to describe exactly how they had changed. Behaviour changes

were also described by parents and young people in terms of feelings of anger and the effects that this had such as lashing out at others and punching walls. In terms of memory issues, parents described feeling like their child had regressed to an earlier developmental stage and consequently needed to be reminded about various skills and routines such as personal care. Children and young people described noticing that they were unable to remember aspects of their school day and therefore could not engage in conversations with family members about this. These issues led to feelings of upset and frustration for parents and children alike.

All children and young people reported a level of challenge in terms of establishing new routines with school work and being able to engage to a level that they once could. They noticed differences in the ways in which they could do certain learning tasks such as handwriting as well as the ways in which they listened and organised themselves.

“Just really bad tempers, really and, and hurting herself too, hitting things, walls, you know were punching.” (Susan, Parent)

“Nobody understands fatigue, there isn’t another person in the world, unless that’s connected to you unless they, they know because it can happen so quickly as well.” (Belinda, Parent)

### **Effect on Family**

Both children and parents talked about effects of ABI on the family. Wider effects of ABI for parents especially included: needing to take time off work, travelling to various appointments and the associated financial implications. Travel and financial implications occurred for a variety of reasons such as needing to attend medical appointments outside

the area and paying for private assessments from professionals or for the support of a home tutor. Effects on siblings were also discussed by parent participants and ranged from jealousy to confusion and trauma associated with the event leading to ABI and the consequences of it.

“It’s not just me, it’s about my family, it’s not just oh Cassie had meningitis and she’s the one that’s left with it, it is my family are you know they have to put up with my moods.” (Cassie Child)

“It just changes your whole view of, whole perspective of everything.” (Janice Parent)

“My family didn’t really accept it, I think that was one of the hardest things too.” (Susan Parent)

### 6.1.3 Theme Three: Knowledge of ABI

#### **Lack of Knowledge**

The effects of ABI were identified by parents as being misunderstood by school staff, for example, as an anger problem, as a naughty child or as hormonal activity and therefore it was felt that this often led to inappropriate strategies being used. Fatigue was also felt to be a significantly misunderstood effect of ABI. Parents of children who had seen an EP and had a statement of SEN also felt that documentation associated with this failed to correctly reflect the child’s needs and was in fact too vague in its description. Despite training, parents felt that some staff members still had a limited understanding of ABI and the subtle effects it can have on particular skills needed for learning. Physical well-being was reported by one parent to be the main concern of the teachers rather than subtle learning skills such as working memory. One parent reported difficulty with extended family in terms of their

understanding about ABI and the fact that there were no visible effects of it. Children also recognised that people at school did not know about their injury, the effects of it and how this impacted upon the approaches used to support them.

“A few of the teachers took it well, erm, some of the teachers didn’t really understand or didn’t know what it was.” (Mike Child)

“They were more concerned as well with his physical wellbeing and any accident or any, any bangs rather than thinking of how it might have affected his, his um, learning.” (Michelle Parent)

#### 6.1.4 Theme Four: Emotional Impact

##### **Dilemma in Feelings**

ABI appeared to have caused different dilemmas for parents, the children and young people in terms of their feelings. For example, feeling grateful that a child survived an incident that caused ABI versus learning to cope with the effects of the ABI and the subsequent changes this can cause - feeling sad or depressed versus feeling happy.

“There’s just something that’s not, not quite the same, not bad but just not quite the same.” (Janice Parent)

“You’re not just gonna be depressed or you’re not just gonna be really happy which is what I’ve learnt is that the two can go together you just have to kind of acknowledge both and remember both but just kind of keep going.” (Beth Child)

## **Types of Emotions**

The types of feelings and emotions talked about by parents and their offspring ranged from frustration, isolation, grief and general feelings of stress and worry. Frustration was reportedly linked to systems within education, notably the process of obtaining a Statement of SEN. It appeared that some frustration was linked to a mismatch between parent's understanding and expectations of what a Statement would mean for their child and the reality of this in school (for example, the expectation of being allocated a dedicated adult for their child). Parents also felt frustrated about the lack of thorough long-term care and follow up from services. Feelings of isolation depended in part on each family's situation such as whether it was a single parent family and if siblings were involved. Feeling isolated was reportedly linked to having siblings who were typically developing and needed looking after as well as not feeling that there was anyone to listen to them as parents of a child with ABI.

Children and young people reported feeling frustrated at the effects of their ABI, having to spend time in hospital away from friends. In addition to this the attitude of some adults in school and having to explain themselves to staff (who, they felt should have known about their needs) caused young people frustration.

“Yeah he's got a statement now erm, but that was such a fight to get it, I had to shout and scream.” (Karen Parent)

“You grieve for the child that you've lost because you get a child back and you're so grateful that your child is alive but it's like a ghost of the child that you had.”

(Belinda Parent)



“Some of the teachers didn’t really understand or didn’t know what it was .... it was just frustrating.” (Mike Child)

## **Support**

The group run by the Specialist OT for parents of children with ABI was reported to be a good source of support by all of the parents who had attended it (4 out of 5).

“That was really good, the parent help group.” (Susan Parent)

### **6.1.5 Theme Five: Views About School Staff**

## **Positive Views**

Overall, children and young people felt supported on their return to school and felt that they had been helped and supported. Following her move to a PRU, one young person reported that her educational experience improved and she reported liking the small group and friendly nature of the setting. Flexibility and communication was thought of as important by parents in terms of their child’s return to school. In discussing desirable qualities, children and parents felt that taking time to understand needs, having knowledge of educational systems, being approachable and caring, listening and having a non-judgemental manner were all positive aspects of their experiences with school staff.

“Yeah it was only 8 in the school, so it was very um one-to-one, you know really interactive and friendly.” (Cassie Child on the PRU)

“The school were very, very accommodating you know they were willing to go along with anything that that um you know was, was suggested.” (Janice Parent)

“Everyone’s been really approachable which has been great.” (Beth Child)

### **Negative Views**

Interestingly, the few negative experiences described were also linked to knowledge and the associated strategies and resources used by the staff.

“She was given an exit card you know to get out of the class which erm they kept forgetting to give her, they also didn’t inform the teachers so none of the teachers knew.” (Susan Parent)

“They were very nice but not actually being very productive about strategies I don’t think and at the end of Jack’s school year, whereas he’s normally been like very, very able in the class, he’s actually gone behind in the class during that school year so his, his learning has very much fallen behind.” (Michelle Parent)

“Sometimes I didn’t have an LSA in my class, which I was meant to.” (Mike Child)

## **6.1.6 Theme Six: Views About External Agency Staff**

### **Positive Views**

Long term support and an interest in the child’s needs was seen as a positive as well as inclusion of the whole family in the professional’s involvement. Regular and open contact with professionals was rated as important by parents. Listening, taking the time to understand and being involved in the school return were discussed as positive qualities and actions.

Being interested, staying involved even if active involvement becomes less (e.g. staying in touch by phone or email), being understanding, having knowledge of ABI, calm, non-judgemental, patient and knowledge of other services and teams to refer children to were all positive qualities described by participants.

“Understanding, patience, caring, time erm, research, erm...” (Belinda Parent)

### **Understanding the Role of Professionals**

Parents generally reported that they understood the roles of professionals involved in their child’s care and only one parent felt that there were people coming and going from meetings whom she did not know or understand their purpose. The Paediatricians and General Practitioners were highly regarded amongst the parents and said to be understanding and helpful in trying to get further support for children and making referrals to other agencies. The one professional involved in all cases was the Specialist OT and every participant spoke positively about her.

Views on the Specialist OT ranged from:

“Erm, she’s nice.” (Billy Child)

To:

“Oh I don’t think we’d have survived without her, not as a family, I think we’d gone under.” (Belinda Parent)

“The specialist OT was fantastic.” (Susan Parent)

All parents found her to be helpful and knowledgeable, not only about ABI but also other services that families and children may need. She was the person identified by all those interviewed as the main source of support since ABI.

Views on the role of the EP varied across parents and were very much based on whether their child had needed to access one and therefore their level of knowledge about that professional group. One parent felt that there should be dedicated EPs for children with ABI. Other parents did not know what the role of the EP entailed.

“I think ABI children ought to have an ABI educational psychologist – I: ok – because ABI children are judged (pause) are judged again on children being naughty.”  
(Belinda Parent)

### **Negative Views**

One parent felt that follow up arrangements with their child’s medical team could have been clearer. Three other parents talked about their views that external agency professionals from an educational background (EPs in particular) offered little new knowledge about their child’s situation, lacked understanding about ABI and/or provided no follow up.

“I think follow-up arrangements though have been quite woolly.” (Michelle Parent)

“It was just out of the blue, happened they saw her, they sent a letter that was it, no more, nothing.” (Susan Parent, on EP involvement)

## 6.2 Research Question Three

What improvements could be made in the future in relation to the schooling experience for children with ABI?

### 6.2.1 Theme Seven: The Future

#### **Qualities of People**

Communication skills were at the centre of what children and their parents thought of as important qualities of those people who supported them. This was a key area they felt could be improved upon based on their experiences. An ability to listen to the expertise of parents as well as talk to children and develop relationships were factors that parents and children felt were most important. Included within this, the older child participants felt that they would have liked to have their desire for some independence recognised.

“I think they should listen more to, to parents ... we know what they need.”

(Belinda Parent)

“I would say study the person, to be honest.” (Mike Child)

#### **Knowledge**

Both parents and children felt that schools and external agency professionals could improve support for children with ABI by simply having a greater awareness of it. This included recognising that ABI exists, understanding that it can have long-term effects and having sufficient knowledge of how to deal with it. One parent thought that the need for raising

awareness could be extended to other children and parents at a generic information or education evening as may be done for drugs awareness for example.

“Yeah awareness yeah, more awareness of it. I think it should be more of a big thing especially with meningitis definitely.” (Cassie Child)

“Well, I definitely think they need to learn more about it, there seem to be real gaps in learning.” (Michelle Parent)

### **Extended Help**

The perceived need for extended support was very much dependent on each individual case and the circumstances of each family. Points raised for consideration by two parents in particular were: the lack of an identified service or person to advise and support once a young person becomes 18 and is transferred to adult services; the potential need for a support worker type of role to guide parents and support them through the statutory assessment process in particular; and support for extended family especially in relation to education about ABI.

“I suppose it would’ve been nice in the statementing, in the statement process if we had like a support worker assigned to us. I don’t know whether they do anything like that but that, that would’ve been quite useful – I: yeah – you know, just someone to liaise coz rather than just feeling on our own, feeling as though we were completely on our own and we were having to do lots of leg work.” (Karen Parent)

## 7 Discussion

In the last section, a number of findings were presented in relation to each of the three research questions. This section will go on to consider these findings in more detail in relation to existing research. Please see appendix L for my overall reflections on the findings.

This research has found that the schooling experience and support received from professionals was described in a positive light overall by all 11 participants. There was a fine balance between positive and negative experiences related to knowledge of ABI and the associated support given to the children. Having knowledge of ABI and its effects and knowing what to do about it appeared to be the most important point raised by child and parent participants. This was because it affected their experience of school following ABI and how they were supported and understood and made for a positive experience or not.

The views and experiences of the participants as arranged in the themes set out above develop our knowledge and understanding of how children experience ABI, particularly with regard to schooling following injury. This was probably most highlighted in theme one: 'first-hand account of ABI' which ranged from reflections on the self and changes in identity following ABI and discussion about peer relationships, to exploration of the effects of ABI such as tiredness and coping with a return to school routine and expectations to complete academic work.

As knowledge about ABI and the associated strategies needed to support children was particularly relevant in making an experience positive or not, the education and understanding of professionals tasked with supporting these families has to be sound. The

findings suggest that this is very important in how a family's experience unfolds, following the emotional stress of the ABI and the difference between child and family in how the event is experienced, remembered and reacted to. The family are a key part of the child's ecological system (Bronfenbrenner, 1979). Breakdown in the microsystem would lead to ineffective support for the child, who would not have the tools to explore other parts of their environment. My findings show issues for the family would need addressing (through support from professionals) in order that they can support the young person too. Ecological systems theory illustrates how the interactions between educational professionals and the family are critical in the provision of effective support for the child post injury.

As set out in the introduction, there is limited research in this area, particularly when addressing the gap of children's views being included. However, there are some similarities with some authors in this area and the themes from the interviews carried out for this research. Firstly, similarly to reports from Armstrong and Kerns (2002) parents in this research reported various feelings and emotions associated with ABI such as grief and guilt. Similarly, reports from parents and the young people regarding the range of effects of ABI (fatigue, concentration, memory, emotional effects) as well as the delayed appearance of some of these sequelae match those reported elsewhere in ABI related literature (Middleton, 2001a ; Walker & Wicks, 2005). ABI was also described by children and parents as a phenomenon that can have hidden effects and this was something also highlighted by Sharp et al. (2006) in their research involving Australian adolescents with ABI.

The findings are very valuable in terms of adding to the existing literature in the under-explored area of childhood ABI. Through a flexible approach to data collection and actively listening to those directly affected, a more thorough and sensitive understanding of this



phenomenon can be developed by professionals. These findings will be of most relevance to the local authority where the research was conducted and the schools and professionals who work there. Having accounts of how services and schools have been experienced by those directly affected by ABI can be considered in relation to future service delivery and joint working between professionals such as the EPs and Specialist OT. Please see the final section in paper two for more detailed consideration about the implications of this research EP practice.

## 8 Reflections on the Research Process

The inclusion and focus upon the views and experiences of children and young people with ABI in particular can be considered a strength of this study given the lack of existing research including accounts of ABI from those directly affected (Crisp, 1993). The chosen data collection and analysis techniques allowed a flexible approach necessary for a topic area that is laced with sensitive and highly individualised needs. The flexibility of semi-structured interviews allowed an authentic account of the first-hand experiences of ABI.

Data was thematically analysed by myself and thus it should be recognised that this is my own interpretation of what participants were saying. With more time to complete the research, it may have been beneficial to ask a colleague to code data as well, although it should be noted that I did discuss themes and my emerging ideas with supervisors and EP colleagues to aid thinking.

I acknowledge that this research represents the views and lived reality of the participants involved and was influenced by the particular time and context of the interviews and therefore would not be exactly replicated or generalisable to different participants or a different area/context. However, these findings are illuminative in terms of aiding development of knowledge and understanding for practitioners and professionals who may be involved with a child who has ABI, on a number of levels or situations. As such these findings could be helpful when working with other children and young people who have experienced ABI.

As a researcher, my past experience of working with adults and children with ABI helped in the interviewing and sampling process because of my knowledge about the varying effects

of ABI and other professionals that I could network with. The challenges in identifying children and young people to take part in this research indicates that ample time and perseverance is needed when engaging this group and seeking to access their views in this area. These challenges also point towards the need for continued work around identification and recording of ABI amongst health and education services (especially EP services who are in the unique position of having regular visits to school and an overview of many children whatever their additional needs) and this has also been identified by others and is an area of on-going need in the field (Walker & Wicks, 2005).

## 9 Conclusion

To conclude, this research has illuminated the perspectives of children and young people with ABI and their parents about this phenomenon and schooling experiences in relation to this. Broadly, positive experiences were reported by all participants. Knowledge and understanding of ABI and therefore how the professionals supported children was identified as key in making a return to school successful and ensuring a positive educational experience thereafter.

Issues have already been raised in this paper about definitions and recording numbers of ABI; the relevance for the EP team where this research was carried out and the other professionals they work with in terms of developing services, knowledge and understanding about ABI. At the end of paper two, the findings from both parts of this research will be considered together and implications for EP practice discussed.

## **Paper Two:**

### **An Exploratory Study Into the Experiences of School Staff and External Agency Professionals who Support Children with ABI**

## 10 Abstract Paper Two

The aim of this paper was to generate new understanding with regard to the factors (areas of good practice, issues & challenges) involved in supporting children and young people with ABI from the perspective of school based practitioners and professionals from external agencies. Semi-structured interviews were used to gather the views of school based practitioners (N=7) and external agency professionals (N=7). Following this, interviews were transcribed and a thematic analysis approach was taken to analyse the data gathered. Interview responses were organised into themes which represented a range of factors, including how professionals worked together, what was positive about their experiences and their hopes for the future. It was found that overall all participants described a positive experience in terms of working with each other and supporting ABI associated needs. A role for EPs in this area was identified and both school based and external agency professionals were looking to learn from the expertise of someone else. All participants agreed that on-going training and collaboration with other professionals would be important for continuing success in supporting children and young people with ABI in the future.

## 11 Introduction

### 11.1 Purpose

This is the second of two papers exploring experiences associated with childhood ABI from the perspectives of school based practitioners and external agency professionals. The purpose is to generate new understandings in relation to the lived experiences of those people who support children with an ABI. Specifically, challenges encountered, feelings of confidence and how experiences of working with other professionals are described will be focused upon.

ABI presents a number of unique challenges for school staff and external agency professionals compared to other SEN that they may encounter. The young person will have developed ways of learning during a period of typical development prior to injury. Due to the location and severity of injury, the impact may not be evident until natural development phases occur. This may lead to failure in developing skills long after the injury has occurred, whilst some knowledge prior to injury may be retained. This has significant implications for the professionals supporting the educational outcomes for these young people due to long term unpredictability. See section 2.2 and appendix A for further definitions and causes of ABI.

### 11.2 Context

Whilst guidance such as the exemplar on ABI called 'Jack's Journey' (Department of Health & Department for Education & Skills, 2004) sets out a co-ordinated and child centred response to ABI from a variety of professionals, there is very little existing research to

develop understanding of how these professionals deal with ABI and how they feel about doing so.

It has also been suggested that paediatric health services need to be aware of the provision available to children in terms of education following ABI so as to be able to successfully advise and liaise with families and education staff (Crouchman, 1990). To what extent or how successfully this actually happens is not clear from existing literature.



## 12 A Review of Literature

This section includes a discussion of literature relevant to professionals and ABI. A detailed literature review has formed the basis for this research and can be found in appendix D.

### 12.1 School Based Practitioners and ABI

Existing literature featuring teachers and the school context is limited. This is despite the demanding nature of the school environment and the suggestion that teachers are the people who spend most time with children in school (Jantz & Coulter, 2007; Savage, Pearson, McDonald, Potoczny-Gray & Marchese, 2001). The potential difficulties facing children with ABI that could influence their performance at school include: changes in attention (Daisley, Tams & Kischka, 2009); memory (Catroppa & Anderson, 2002); information processing speed (Walker, 2009); and executive functioning (Anderson & Catroppa, 2005; Powell, 2004). Not only could this affect a child's ability to make sense of the varied information in their learning environments, but it is likely to cause challenges in how teachers present learning tasks to them. For this reason, the school context is important to consider when exploring the literature.

Literature focusing on school staff comes from a variety of locations such as the United States of America (Savage, Depompei, Tyler & Lash, 2005), the UK (Jones & Johnson, 1994; Hawley, Ward, Magnay & Mychalkiw, 2004) and Australia (Sharp et al., 2006) and also includes books of a practical nature (Walker & Wicks 2005; Walker, 2009). Collectively, these sources suggest that ABI is often unrecognised by school staff, misunderstood and is an area where knowledge needs to be developed. It appears that there is concurrence between UK and Australian researchers that teachers require more training and education.

Firstly, Hawley et al. (2004) found that despite teachers reporting children with ABI as having difficulties in learning, one third of the 67 teachers were unaware that the child had experienced a brain injury. The authors suggested that teachers in their study were rarely aware of the ABI. Similarly Hawley, Magnay and Long (2002) found that teachers rarely made additional arrangements for children with what may be termed the 'hidden effects' of ABI compared to peers who had visible physical effects. Hawley et al. (2002) recommended that teachers should have a list of potential cognitive and behavioural needs following ABI. Collectively, these studies suggest that a two-fold approach is necessary, firstly ensuring that school staff are aware of the ABI occurring and secondly that they should have knowledge on the range of potential effects and how to support these. The similarities between these studies in the UK education context is good at developing our understanding of issues around ABI and schooling.

Secondly, Sharp et al. (2006) in Australia highlighted the importance of improved knowledge and education of teachers with regard to the effects of ABI, especially during a young person's transition period from a hospital to school environment. Whilst generalising these findings to a UK educational context needs consideration, it does appear that literature across regions agree that teachers need to know more about ABI in general; highlighting it is a potential area of importance.

To summarise, what little literature exists with a focus on the school context suggests that teachers do not know enough about ABI in general and that children have difficulties with learning associated with the effects of ABI. However, what is not clear from existing literature is how school staff describe their experiences of supporting someone with ABI, what they see as the key issues, who has supported them and how the overall experience

has unfolded. Such information would complement and extend existing literature as well as contribute to improving practice, training and support of ABI.

Next, existing knowledge about the roles and experiences of external agency professionals in relation to ABI will be explored.

## 12.2 The Role of External Agencies in ABI

Research concerning the role of external agencies supporting children, families and schools around ABI is also limited. However, three studies with EPs as participants have been found and will be the main focus for this review.

Based on quantitative data collected through rating scales completed by EPs, Brooks et al. (2003) concluded that children who have ABI receive adequate support for their needs.

Based on the little research that exists and what the authors' admit was a low response rate from EPs, this is a sweeping generalisation to make. The authors failed to ask the most important people about whether they felt adequately supported; the parents and children themselves. The methods used did not allow the EPs to express their thoughts in detail outside of a rating scale. For these reasons, this study adds little to current understanding of the schooling experiences of children with ABI or the issues that face the professionals such as EPs in supporting them.

The work of Brooks et al. (2003) was improved upon by Bozic and Morris (2005) who explored the role of Educational Psychology Services in the recovery of children with ABI through a small-scale questionnaire based survey. Bozic and Morris reported that most participants felt their initial training in Educational Psychology provided little if any preparation for this area of professional practice. The researchers also reported that EPs

were the professionals most frequently approached for support and advice prior to a child's return to school following ABI. This study is a good addition to the ABI literature and can be considered significant because of the focus on the role of EPs and their future practice in this area. However, as acknowledged by Bozic and Morris themselves, the views of other key people involved in the support and education of children with ABI such as teachers, parents and the children themselves were not included in their research.

Recently Ball and Howe (2013) have included the views of a variety of external agency professionals (including EPs) based in a specialist rehabilitation centre and a children's hospital. They aimed to consider the role of EPs in supporting children with ABI and the process of reintegration into school. By exploring themes from semi-structured interviews with professionals, the authors were able to make a number of recommendations for EP practice in relation to ABI. These recommendations were linked to the need for improved communication between professionals and more training for education staff. The strengths of this study include the focus on reintegration into school, the variety of professionals and the data collection method which allowed flexibility in questioning. It is a recent addition to the wider field of literature existing on ABI. However, the lack of school based professionals means that it is unknown what they considered the transition process to be and what would be useful in helping them in supporting the children. This is important knowledge given that EPs are key professionals in supporting schools to build knowledge and adjust practice.

Aside from the recent work of Ball and Howe (2013), other research including external agency professionals other than EPs is even more limited. Research about OTs was found but not pursued because it was regarding adults' return to work following ABI (Conradie & Ashleigh, 2008). In the USA, Frank, Redmond, Ruediger and Scott (1997) surveyed the

equivalent of British Speech and Language Therapists (SALT). It was found that the speech-language pathologists did not feel confident working with children with ABI and that multi-agency working could be better.

What is known from the research regarding external agencies is how some EPs reported the experience of working with the issues around ABI. However, conflict exists within this research. What is unknown is further detail about who else the EPs worked with and their overall reporting of experiences in terms of working with others, school based or otherwise. There is limited knowledge of how other professionals describe their experiences, although clearly Ball and Howe (2013) have started to add to this with their recently published research.

There appears to be a theme within the existing literature concerning both schools and external agencies that not enough is known about ABI and that training is needed. There are materials such as Walker (2009) and Walker and Wicks (2005) with a wealth of information from a practical, educational focus that could be useful to school staff and external agency professional, as well as publications by charities such as CBIT. However, what is not known from existing literature in this field is whether professionals have access to and use such information, who supports them and how confident they feel in their abilities to support these children. To develop education, training and communication, more knowledge about people's experiences, important factors in them being able to carry out their jobs and their views about future improvements is needed.

## 13 Research Aim

Through reviewing existing literature within the field of ABI and specific to the roles of teachers, external agencies and the school context, it is evident that little is known about how these people describe their knowledge and experience of ABI. Therefore, this research will focus on gaining the views of those professionals tasked with supporting families following ABI. The general aim of this paper is to explore the views and experiences of school based practitioners and external agency professionals to illuminate the factors involved in working in the field of ABI and supporting those people dealing with its impact.

In detail, this includes the following research questions:

1. In what ways do professionals support children, young people and their parents following ABI?
2. What are the perceived views and experiences of professionals working with children who have experienced ABI?
3. How could support offered by these professionals be improved upon?

## 14 Methodology

### 14.1 Research Design

As the views of school practitioners and external agency professionals are central to this study, a flexible research design consistent with an interpretive approach and social constructionist philosophy was used (see paper one). Due to the challenging and wide ranging effects of ABI in children and young people, along with the limited existing research base, this part of the research also required a flexible approach.

This part of the research can be described as a qualitative inquiry (Robson, 2011). The advantages of a qualitative approach include being able to immerse oneself in the data so as to be able to capture and discover the views and experiences of the participants. In terms of methodology, illuminative enquiry (Burden, 1998, see paper one) was used as an approach to exploring the situations and experiences of participants in relation to their work with young people who have experienced an ABI. It is acknowledged that qualitative inquiry could be criticised for often small sample sizes and a lack of generalisability (VanderStoep & Johnston, 2010). However, an exploration of the unique experiences of professionals in an area of childhood development that is under researched offers interesting discoveries for the future, both in terms of research and EP practice in particular.

### 14.2 Participants

The research took place in a local authority in the South West of England. There were a total of 14 participants; seven school based practitioners and seven external agency professionals. The ABI exemplar 'Jack's Journey' (Department of Health & Department for Education & Skills, 2004) was used as a point of reference in terms of considering the types

of professionals I wanted to approach. I was successful in recruiting some of the professionals outlined in the document such as EPs, a Clinical Psychologist (CP) and a Specialist OT. However, others such as a SALT proved more difficult to identify and recruit. An opportunistic sampling technique was used to identify participants and recruit as the research progressed. All participants were recruited through written communication and then followed up with telephone contact. Due to the nature of ABI as a low incidence SEN, the approach to sampling participants was flexible. Particularly as this is an under researched area, I did not want to impose a strict criteria for successful participation in the research. All participants were required to have experience of working with children and young people who had ABI and work in a school or external agency service that served the local authority. As indicated above, some difficulty was experienced in recruiting participants in that I was able to identify people who had experience in this field but I was not successful in obtaining a response.

### 14.3 Data Collection

The aim was to obtain authentic views from the participants while avoiding influencing their responses. To achieve this, hierarchical focusing (Tomlinson, 1989) was used to construct the two semi-structured interview schedules (see appendix F). Semi-structured interviews were considered to be a good method for data collection because of the flexibility in being able to direct the process, whilst still being able to be specific in terms of the information I wanted to discover (Denscombe, 2004). Rather than using a structured interview schedule, questionnaire or focus group (that employ more restrictive questioning and potentially time limited responses from each individual), semi-structured interviews were considered to be the best forum for participants to discuss personal views and opinions about a currently



under-researched topic. Given that semi-structured interviews are a method through which rich and detailed aspects of individual experiences can be uncovered, other data collection methods such as those mentioned above were discounted. Using the semi-structured interview method ensured questions could be prepared in advance, focusing on relevant topics whilst providing freedom to develop areas of questioning (Robson, 2011). Two pilot interviews were conducted; one with a school based practitioner and one with an external agency professional. The pilot interviews allowed me to practice the interview schedules with participants experienced in working with children and young people with ABI. Some slight changes to wording of questions was made (see appendix F). However, the interviews were kept in the overall analysis due to the small sample size and the opportunity to include the unique views of professionals involved in work with children who are under-represented as a group in the literature.

Interviews were conducted in a location convenient for participants between July and December 2012. The location of interviews was flexible, based on the needs of participants (appendix E). All interviews were digitally recorded, transcribed and read by me (see appendix G for example transcripts).

#### 14.4 Data Analysis

Thematic analysis (Braun & Clarke, 2006) was selected for its flexible approach to theme identification within qualitative data (see paper one). Codes and themes were derived from the data through an inductive approach and the codes, themes and memos were organised using Nvivo 9 (see appendix H).

Interviews were coded separately, the codes reviewed and then combined as they covered many of the same topics. This also added to the anonymity in that individual responses and experiences were less identifiable when combined into similar thematic 'stories' with that of other participants. The demanding nature of qualitative data analysis in terms of time combined with the time constraints of this piece of research meant that it was not possible to include a layer of inter-rater reliability. However, I did spend time reflecting and discussing the experiences of participants and themes as the analysis progressed with academic and EP supervisors.

#### 14.5 Preparation and Ethical Considerations

Approval from the University of Exeter's Ethics Committee was sought and obtained prior to data collection (appendix I).

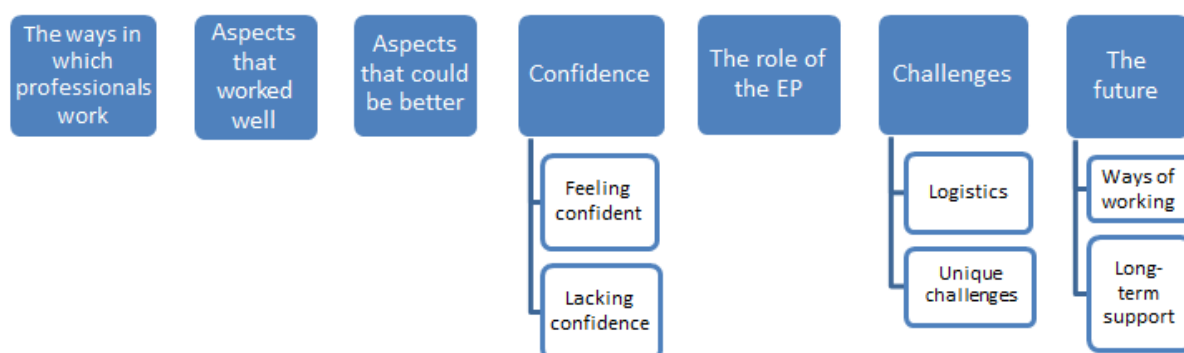
Informed consent was gained from all participants after they had the opportunity to read the necessary paperwork (appendix J). Names have been changed for the purposes of transcribing and reporting on data. Due to the size of the local authority and the fact that EPs were interviewed as well as discussed in detail across interviews, I had to consider how to write up the research in a careful and professional way. Therefore, some specific people that were talked about were referred to in transcripts as 'they' or 'them' to further protect identities of particular people.

Finally, consideration was given to how I would present myself as researcher and explain my role, especially to schools who may have heard of me as a Trainee EP for the service.

Communicating with potential participants in a consistent and timely manner was essential.

## 15 Findings

This section will discuss the themes created as a result of the thematic analysis. A descriptive exploration of each theme that emerged will be presented in relation to each of the research questions (see appendix K for additional quotes).



### 15.1 Research Question One

In what ways do professionals support children, young people and their parents following ABI?

#### 15.1.1 Theme One: The Ways in Which Professionals Work

All participants had worked directly with a child(ren) who had experienced ABI. The participants all had face to face contact with children and families and 10 of them talked specifically about supporting the family in their role, for example, helping the family to understand the effects of ABI, signposting them to others services and being a point of on-going support and advice. However, not all participants experienced face to face contact with other professionals and in some instances contact was through correspondence or telephone. Direct work with families varied depending on the role of the person being interviewed, but broadly encompassed: assessing the needs of the young person,

information giving and teaching related both directly to the ABI as well as the general participation and progress of the young people.

“Teaching functional skills at home if they have physical disability which would include all the daily living activities right through to catching a bus ... it’s very functionally based.” (Anne Specialist OT)

“Often around assessment and advice to schools.” (David EP)

Visiting schools and working directly with school based practitioners also depended on the role of the participant. The Specialist OT was the only person whose role straddled the health and education sectors. Other health service professionals had less direct involvement with schools. Without an established relationship or routine of visiting a school, these participants reported finding it difficult to make connections.

“We try to work with schools but it’s quite difficult getting into school just physically in terms of time wise, but also we don’t have all the links with schools that perhaps other services do.” (Hannah CP)

School staff talked about the importance of relationships with their school based colleagues in terms of sharing information about a young person.

“Probably the teacher and the TAs but also ensuring that everybody else in the school, is fully aware ... to make sure that everything is running smoothly and that they’ve got information that they need.” (Stephanie Primary Special Educational Needs Co-ordinator [SENCO])

Finally, school staff discussed being involved in the child’s return to school. For SENCOs this was at an organisational level whereas support staff supported the child during and beyond the re-integration period.

## 15.2 Research Question Two

What are the views and experiences of professionals working with children who have experienced ABI?

### 15.2.1 Theme Two: Aspects That Worked Well

Overall, positive experiences outweighed negative. Generally, experiences of external agency professionals working with school staff was positive, especially once the school staff had knowledge about ABI. Overall, it was possible for external agencies to successfully make contact with schools. School staff felt that within their working environments they could share information and responses from colleagues were positive.

“I have been round loads of schools now and, and some schools are building up quite an expertise and they will ring as soon as they’ve got a brain injured person.” (Anne Specialist OT)

“It’s having that on-going dialogue and I think as a school that is something that we’re really good at because it is about the children so really positive.” (Kelly Primary Teacher)

Participants working for external agencies had positive views and experiences of EPs.

Communication skills were talked about positively; school staff appreciated external agency professionals being the link between school and home, in arranging and delivering training and engaging with concerns.

The Specialist OT was highly regarded by those who had worked with her. It was her expertise, calming and encouraging approach and regular contact that was appreciated.

“When I have worked with one of the EPs in particular at a secondary school ... it’s been really valuable.” (Anne Specialist OT)

“So we really value either the ed psych report that is done or the specialist OT’s report.” (Kay Secondary SENCO)

### 15.2.2 Theme Three: Aspects That Could be Better

Lack of advice, poor organisation and communication within schools were identified as areas of dissatisfaction. Limited support from others within school (e.g. the SENCO), difficulty communicating with schools (secondary school), misunderstanding of ABI and the willingness and/or ability of schools (secondary) to make adjustments for a child with ABI were all negative issues reported.

“I think the difficulty in secondary schools is that they don’t assign one person to be the TA for an individual child ... sometimes the children with additional needs get lost within a secondary school environment.” (Nicola Paediatrician)

Lack of human resources was also raised as a concern especially in relation to the Specialist OT and EPs:

“There aren’t enough OTs, there aren’t enough Ed Psychs.” (Anne Specialist OT)

Correspondence and follow up from a hospital outside of the local area was raised as an issue by two participants. One SENCO also felt that communication between hospitals and schools could be better and similarly an EP highlighted that she rarely has updates from medical colleagues:

“I always like it if you do get a feedback from the clinical team, be but you never do.” (Miranda EP)

### 15.2.3 Theme Four: Confidence

#### **Feeling Confident**

Confidence of school staff was linked to external agency professionals and the support and training they had been given from these professionals. Confidence of external agency professionals was very much linked to their previous experience and knowledge of brain injury.

“Well I would say almost more because of the specialist OT because we have these regular meetings.” (Kay Secondary SENCO – feels more confident supporting ABI compared to other SEN)

#### **Lacking Confidence**

A lack of confidence reported by participants was related to their knowledge about a child’s particular needs, areas of a young person’s strengths and weaknesses and the strategies they had to be able to address these.

“In terms of me offering advice to the next teacher because like I’ve said, I don’t feel particularly confident about the way that I’m managing him I’m not gonna feel confident about passing that information on.” (Claire Primary Teacher)

Overall, it seems that confidence is related to an individual’s experience, knowledge about ABI and support from others.

### 15.2.4 Theme Five: The Role of the EP

The majority of participants (11) believed there to be a role for EPs supporting childhood ABI. There were strong views that EPs could be a source of support for schools in this area.

Types of support suggested included: attending meetings, delivering training, assessing the needs of children and supporting the implementation of strategies. One teacher commented that there should be more EPs available:

“Definitely, more Ed Psychs in school.” (Kelly Primary Teacher)

EPs were also described as:

“A hugely valuable resource.” (Nicola Paediatrician)

Three participants were less sure about the role of the EP. Interestingly, one of them was an EP; they recognised a statutory role and their doubt was related to their confidence about ABI generally.

“I mean obviously we’ve got a statutory role in that sometimes we have to assess children and as I’ve indicated before sometimes I don’t think I’m contributing anything else.” (David EP)

A primary teacher and secondary TA were the other participants unsure about a role for EPs. The teacher talked about her previous experience of EPs in relation to the usefulness of reports and her understanding of how to address a child’s needs based on the resources available to her.

“I don’t know educational psychologists or when we have external agencies coming in to offer advice very often they’re used to working with that child one to one or they don’t have the classroom hat on.” (Claire Primary Teacher)



### 15.2.5 Theme Six: Challenges

#### **Logistics**

Time constraints and the feeling that there is never enough adult support for children with an ABI was raised as an issue. Equipment and resources linked to the roles of some external agency professionals was also raised as a concern in terms of budget restrictions and being able to order current assessment materials.

Reconciling different viewpoints and maintaining professional boundaries, especially for external agency professionals, who may be looked upon by parents as a key part of a child's recovery was discussed as a challenge.

“Holding your professional role ... marking the boundaries.” (Emily EOTAS)

The Specialist OT discussed measuring the effectiveness of her service and the challenge this presents. The challenges of forming a multi-agency team and communicating effectively and efficiently (as it is made up when needed and so professionals come from various teams) was also discussed.

“I think the difficult thing is communication because we can be, there might be a physio from the Child Development Centre, and a speech and language therapist from a health centre and a psychologist from somewhere else so communication is made harder.” (Anne Specialist OT)

A primary teacher also mentioned measuring their effectiveness in relation to a child's absence from school and how it is difficult to monitor progress when attendance is sporadic.

“There are also attendance issues with him so it's not as if you can put something in place work with that and see if that's had an impact because he'll only be there for part of it so you never really know if that's had any impact.” (Claire Primary Teacher)

Developing knowledge and understanding about ABI and then sharing this with colleagues was identified by many school based participants as a challenge, particularly for secondary school colleagues due to the frequent changing nature of that environment.

“Passing that information to already overloaded teachers was not difficult because as I say they were understanding but I had to keep reminding them you know.”

(Emma Secondary TA)

Primary school based participants considered the challenges of explaining a child’s ABI to other children and the need to ensure an appropriate level of information was given across the school based on the ages of all of the children.

“Informing all the rest of the school, all the children, right from class R, right the way through, of what’s happened ... then that’s got to be tailored, you can’t do a whole school presentation.” (Stephanie Primary SENCO)

### **Unique Challenges**

The range and severity of effects following an ABI some of which described as ‘unseen’ was raised as a unique challenge by all participants. Issues with processing, attention, memory, impulsivity, and fatigue as well as physical effects such as immobility were discussed by participants. Seeing these needs within the context of ABI was thought of as important to avoid other potentially unhelpful labels for a child’s presentation.

“Yeah my concern is, if ... some of the things that are being picked up and his attentional difficulties and concentration, if they’re not seen in the context of a brain injury, then ... he could get a label that’s not very helpful in terms of schooling.”  
(Harriet CP)

Knowing how to manage the impact of ABI within typical classroom behaviour management strategies was felt to be a challenge. In addition to this, the potential interaction of ABI and social factors and the consequent impact on a child's functioning was identified as a difficulty.

“They are very difficult children to manage because you never know whether you are making allowances for them or whether they genuinely can't do something.” (Claire Primary Teacher)

An EP felt that existing ways of thinking about SEN, teaching and the assessments used by professionals are not necessarily relevant to ABI, or address the unique needs of these young people.

“Our models of how to teach children with additional needs I think are very different for children with brain injuries and often they are good at the sort of assessments that we do with them but they're poor at metacognitive skills so we can often give a very misleading picture of their abilities.” (David EP)

### 15.3 Research Question Three

How could support offered by these professionals be improved upon?

#### 15.3.1 Theme Seven: The Future

##### **Ways of Working**

Participants wanted to work with each other more around the issues of ABI such as on-going monitoring and review of the children's needs specifically related to learning, the strategies that teachers could use and how and when to get more information. In particular, working with EPs more in terms of assessment and intervention was suggested by school based

practitioners and external agency professionals. This was an area that all participants wanted to improve in terms of the amount of joint work and on-going advice from their EP. An EP suggested that a 'virtual' multi-agency service called upon when necessary may meet this requirement.

"So developing specialisms within a service rather than setting up a specialist service, a sort of virtual service as and when it's needed can be called into place I would think would be the best use of resources." (David EP)

All participants agreed that more awareness was needed around ABI. This ranged from awareness raising on initial teacher and EP training courses to on-going training relevant to the school environment and knowledge of teachers.

"I think it always comes down to training, just more training, more information really." (Jane SENCO)

School staff were keen to emphasise that joint work between schools and professionals needs to be child centred. This included the need for understanding the context within which the child functions as well as respecting the professional opinions and knowledge of others. One SENCO linked this to her previous experience of working alongside health professionals.

"Paediatricians seem to still be the one group that actually never come into school to observe children in the setting where, let's face it, we spend more time with them than anybody else." (Carol Primary SENCO)

Participants suggested a combined approach of having information readily available to them in the form of an information pack whilst also having access to an 'outside expert' who could offer advice over time.

"I just think that you know, you have got to have quality advice, yes you can build capacity but you actually have to get that, you know, outside expertise to enable you to do that in, to enable staff to become skilled up." (Carol SENCO)

Similarly, one teacher suggested that practice could be shared within a school environment through an information book to include child specific and general information about ABI.

"I think as a teacher, I think every time that child moves on to a new teacher, the new teacher needs to have some kind of training or some kind of information package about their needs and about things that have worked well." (Claire Primary Teacher)

Some participants talked about the need for improved liaison between services, for example, between school and EOTAS tutors; between school and health colleagues; between hospitals and between external agency professionals (e.g. EPs to Paediatricians).

"We didn't have a lot of contact with the home tutor which maybe that could be, could be improved upon thinking about it." (Stephanie SENCO)

"We don't always get the information from hospital appointments ... so I think being more transparent and open between the two groups of professionals would make things a lot easier." (Jane Secondary SENCO)

## **Long-Term Support**

Long-term emotional support for parents was identified as an area that could be targeted in the future.

“In a couple of cases the parents of children with acquired brain injury carry a large degree of anxiety around and I think there’s a broader role, maybe not for educational psychology but certainly people working in the field of mental health to support parents around that.” (David EP)

The potential of the primary school setting was highlighted as being able to provide academic and nurturing support for children as well as education for the families.

“I think that’s where the best of primary schools are coming in aren’t they because they’re there to, to nurture as well as to academically sort of educate their children um, it’s, it’s a wonderful opportunity to love families that need more support, it’s not just the children, it’s the parents.” (Emily EOTAS)

Finally, EPs were identified as professionals who could offer long term support in terms of raising the issue of ABI with teachers as well as the children and young people directly.

“I mean I don’t know maybe in an ideal world if the Ed Psychs are going around the schools they could perhaps mention it to the teachers.” (Sadie Nurse)

“Whether the educational psychologist could have the role in terms of expressing to the child well no actually this this is what happened to you, this is what it looks like.” (Miranda EP)

## 16 Discussion

This section considers the findings of the existing research and considers the overall process (see appendix L for reflections on the findings).

This research has found that all participants described a positive experience of working with each other in school and with external agencies. School staff valued the expertise of outside professionals including EPs, although it was not unanimously felt that there is a role for EPs in this area. Interestingly, most external agency professionals felt strongly that there was a role for EPs in ABI support apart from one participant who was an EP.

The need to raise awareness of ABI amongst other school staff, external agency professionals and parents was agreed by all participants. The unique challenges were identified as subtle cognitive or emotional needs and the changing nature of the injury over time. It was agreed that these would need to be focused on in the future in terms of changing practice and developing knowledge.

All participants desired further training on ABI to develop their understanding of the key issues. The school based staff looked to draw on the expertise of the external agency professionals, highlighting the need for specialist knowledge within these teams. Due to ABI being a low incidence SEN with a potentially complicated impact, all participants felt it was important to keep their knowledge up to date through regular reviews. Raising awareness amongst the children's workforce and parents at a very general level was agreed upon by all participants as an important future requirement.

As explored in the literature review, previous research (Hawley et al., 2004) has reported that some teachers have no knowledge of a child having an ABI. When teachers have

known, it has been reported that children who do not have visible effects of injury are treated differently to those who do (Hawley et al., 2002). In contrast, the findings reported here suggest that there was greater awareness of ABI (and its distinction from other SEN) amongst school based practitioners than previous research suggests and that they sometimes feel confident in dealing with it. The findings illustrated a desire amongst teachers to further develop their knowledge of ABI. However, it is interesting that this knowledge seems to fall into two categories. Firstly, through some participants' responses, it was clear that their knowledge is more limited than implied by their responses. For example, one participant said that the child made a full and complete recovery and rated their confidence in dealing with ABI as high compared to other SEN. This suggests that they have limited knowledge and understanding (in terms of ever fully recovering from ABI), but falsely believe they know a sufficient amount to be able to deal with the issue effectively in the classroom. Whilst there was a level of basic awareness, this statement suggests that a deeper understanding in relation to a child's educational needs following ABI in the long-term is lacking and as such may lead to inappropriate support.

Secondly, there were participants who realised that they had limited understanding and support from others and consequently were realistic in their feelings of confidence in dealing with ABI and its consequences.

It is possible to explain both of these scenarios through the Johari Window (Luft, 1969). This is a tool used to help individual's understand themselves. By claiming that a child has made a full and complete recovery, it could be suggested that whilst some participants believe they have a good understanding of ABI, they are in fact in the blind quadrant of the Johari Window in terms of the knowledge they have and their understanding of this compared to



others (i.e. me as researcher). Contrastingly, other participants who realised that their knowledge was limited could be described as being in the open quadrant.

There are multiple layers of supporting professionals in the ecological systems model (Bronfenbrenner, 1979) which interact to provide the required support for the child or young person after ABI, and the current findings show positive experiences amongst professionals of different disciplines when working together to achieve this. For the support to be most effective the professionals need to be within the open quadrant of their Johari Window (Luft, 1969), sharing a common level of understanding of ABI and the challenges it poses within an educational context to be able to support the child effectively. The findings reinforce how much external agency professionals and school staff rely on each other when supporting the child or young person and suggest that the microsystem is largely working well for these children. The quality of their overall interaction with the child is defined by their level of knowledge and understanding of ABI, and this should be developed and managed through specific training.

In terms of existing research about external agency professionals, particularly EPs, there are some similarities with the current findings. Bozic and Morris (2005) reported that EPs do not have sound knowledge within which to base their practice in the area of ABI and as such can lack confidence. The EPs interviewed for the current research concurred with this in terms of their level of confidence and a lack of training on initial EP courses. However, as Bozic and Morris also found, other participants in my group (both school based & external agency) were looking to the EP for on-going 'expert' advice.

Ball and Howe (2013) discussed the role for EPs in ABI, particularly in terms of facilitating communication between professionals and supporting the on-going education and training

of other professionals. Ball and Howe clearly identified a role for EPs and whilst some of my participants agreed (e.g. school staff looking for advice and external agency professionals hoping for increased joint working); it was not unanimously agreed upon by all. It was an EP who said that they were not sure of the role for EPs in supporting ABI and this was in part due to their lack of confidence and knowledge of this area. This is likely linked to how they view and assess SEN in terms of what they see the role of the EP to be and how they can contribute. The other EP thought that there was a role although did not feel personally confident in this area and identified that more training is needed. However, the way that both EPs described their work in the area of ABI to date implied that they did not see themselves as key figures in the support network for the child and family. Neither EP appeared to describe their skills as particularly unique or special as compared to other professionals. They described other professionals as people who were holding key information, EP involvement as time limited and based on recommendation making following a 'test and run' type approach.

Based on their knowledge (which is linked to factors such as where they trained, where they have worked and amount of experience) the EPs appeared to have made assumptions about ABI based on their existing views and beliefs of the role of the EP and ABI. It is not clear from the answers given by the EPs interviewed for this research what their underlying models of SEN are and it seems that they are not confident in this either. However, by describing scenarios of assessing and recommending with little interaction with other stakeholders or follow up, a medical model type approach is implied. This has training implications for developing knowledge of ABI, what the role of the EP could be in this area

and what significant potential their skill set as psychologists has to offer all those affected by ABI.

## 17 Reflections on the Research Process

This research has strengths in terms of the wide range of professionals interviewed and the different workforces they represented. The findings will be valuable to those professionals and the services they work for within the local authority, particularly for the EP service and the recommendations linked to this for future practice (see below).

The aim of the research was to discover the views and experiences of the professionals who have to support the impacts of ABI. The use of a qualitative approach allowed the research to be data driven and guided by what was felt to be most pertinent to each participant.

Whilst it should be noted that the data was analysed by me and therefore represents my interpretation, the findings are still representative of the experiences of those people interviewed and therefore add to the existing literature. See appendix M for considerations for future research.

## 18 Conclusions of Paper One and Two in Relation to EP Practice

The research reported in paper one and two contributes to the knowledge base on the key issues facing young people with ABI and their support network of parents, school based practitioners and external agency professionals. This section will summarise the findings from both papers and give consideration to the implications for EP practice.

To summarise, the main themes and findings from papers one and two were that:

- there are long-term and unique consequences of ABI that require on-going monitoring.
- overall all participants described a positive experience in terms of the support they received or how they worked together with others.

However, it was agreed that this positive experience relies heavily on knowledge and understanding and as such:

- there is a need for on-going training and education across all aspects of the child's ecological system.

The EP was largely seen as an appropriate professional to be involved in this.

Through uncovering the narratives from the young people's perspective, their parents and the professionals tasked with supporting them, it has been possible to ascertain what currently works in their support system and what needs to be improved upon, such as developing general awareness of ABI. These findings offer a contribution to knowledge about the occurrence of childhood ABI and its effects, as well as a contribution to practice in terms of knowing more about how EPs can work in this area.

The specific contributions to knowledge can be outlined in terms of the first hand account of ABI from the children, the feelings of parents associated with ABI, the on-going effects that an ABI has and the role of the EP. The difference in how children described their peer relationships following ABI was a particular area of interest and contribution to knowledge. Whilst boys were able to identify changes within themselves following ABI, they felt that their relationships with peers were stable. Contrastingly girls could identify changes within themselves and their friendships and consequently these changed over time. This offers a contribution to knowledge in terms of how peer relationships are described and experienced by young people and the different support that may be needed for girls and boys.

Giving parents opportunity to express their views and feelings also indicates a contribution to knowledge from the findings particularly in terms of their emotions following the incident. Knowing that parents experience grief, loss, anxiety and face hostility and lack of support from extended family adds to understanding the impact that ABI has on a child's microsystem and therefore areas that may need on-going support and intervention from a group of multi-agency professionals.

The detailed information about the effects of ABI offers a contribution to knowledge. The issue of fatigue was highlighted by participants in both papers as a significant effect post ABI that impacts on children's learning, personality and ability to engage with others. This clearly has implications for a child's participation at school and therefore the expectations that staff have of them to participate. Finally, the findings offer a contribution to knowledge with regard to the role of the EP. Most participants in both papers felt that there was a role for the EP in the area of childhood ABI. They wanted the support of the EP

with the issues linked to ABI and generally reported valuing the support of EPs, especially when this was part of a multi-agency approach.

However, as discussed in previous sections, the role of the EP and utilisation of this may be dependent on the EP, their existing ways of working, models of SEN and knowledge of ABI as to whether they become involved and feel confident to have an on-going and significant contribution. Therefore ABI needs demystifying to an extent to show that whilst a basic level of awareness is needed, as EP, one does not need to be an expert of the brain or injury of it to make a contribution. Rather, the EP has a number of skills that can be used to support the child and their microsystem.

Therefore, this current research has contributed to demystifying ABI. It has been explored why ABI has a set of unique effects different to other SEN; established why a basic level of knowledge about ABI is needed and that more training is needed (as is often the case with other areas of SEN and specialist teaching) but aside from this the most important factor is what EPs do and how families are supported. Therefore, part of the initial training and awareness raising about ABI for EPs in particular is to help them to see that they have a role in this area.

Based on this contribution to knowledge, there are various practical implications for EPs particularly in terms of changing how they think and practice in this area. Firstly, it is recommended that within EP teams, an ABI specialism is developed. It is acknowledged that ABI could be described as a low incidence SEN. When it does occur, it requires a certain level of knowledge and understanding about the developing brain and the impact injury can have. The benefit of having a specialist within an EP team is two-fold; they could be called upon for consultation, supervision and work at a systemic level. Secondly, they could raise

awareness within their own team and provide a level of basic training on the issues around childhood ABI to other EPs. This would need to include consideration of how an EP's skills can be used to support this area which most participants in this current research clearly appreciated because they felt strongly that a role for EPs exists.

Due to the long-term and changing nature of the needs that ABI can leave children and families with, it is recommended that the EP facilitates regular and on-going multi-disciplinary reviews between schools and external agencies. This could be accommodated through existing plan-do-review or planning meeting formats. The EP has consultation skills to facilitate the knowledge development of school staff and ensure involvement of parents in relevant discussions.

The EP has a distinctive skill set (Cameron, 2006) that can be applied to ABI and support people in evaluating their knowledge and what training needs they have. As such, the EP could have a role in supporting others to reflect on their current practice and where necessary open new quadrants of their Johari Window (Luft, 1969). In turn, this develops the ways in which children and young people with ABI are understood and supported by ensuring the adults in their microsystem (Bronfenbrenner, 1979) work effectively together.

It is suggested that knowledge from the current research indicates that effective support in school for children and young people with ABI will need to be two-fold. This is due to a differing level of knowledge and understanding amongst the children's workforce. Firstly it is important for adults supporting young people with ABI to have a basic level of understanding about the nature of day to day issues. This will help with providing extra support if needed in the classroom. In addition to this, a longer term approach in terms of



on-going communication and deepening knowledge of ABI and its consequences will be needed due to the potentially unpredictable and long-term nature of an injury.

The short-term responses to issues by professionals and parents will be important. These people need to feel confident in identifying a child's needs and know which professional to contact for advice. This could be achieved through a basic information pack owned and produced by the EP service as well as a directory that supports parents in understanding their local authority services. With the evolving field of SEN, the requirement of a local offer (Department for Education, 2013) will mean that local authorities and health services will need to clearly set out the provision available across education, health and social care. In addition to this the requirement of the new Education, Health and Care Plans (Department for Education, 2013) for children with complex SEN will require teams of professionals to work in more integrated ways with parents and the child as a central focus. As per this requirement, a virtual ABI service would be ready to work together and offer support through such a plan if and when needed.

With regard to longer term support, EPs have an important role in terms of strategic planning with other services to develop support networks for school based practitioners and parents in particular. This would be especially important over time as the child develops and the potential for changing (or increasing) needs arises. On-going multi-disciplinary review and feedback would also allow for classroom practice to be adapted where necessary.

Finally, it is recommended that more focus is placed on adequate monitoring and recording of ABI occurrence. Whilst the EP service in the local authority where this research was conducted had some paper records of children known to have an ABI this was not only

difficult to search but also limited in its content. It was also particularly challenging to establish numbers of ABI in the local area and so a shared statistical database that can regularly be updated would be beneficial. This recommendation is likely to be applicable to other local authorities and the healthcare trusts they work with.

The complexities of ABI highlighted through the narratives and lived experiences of the current participant group within this study, have also been considered alongside the role of the EP, how they can facilitate future practice and improve the educational experiences of young people. As a result of the findings in this study, future research (appendix M) should focus on expanding existing work and in turn keep ABI on the agenda as an area of EP knowledge and practice.

## 19 References

Aitken, M. E., McCarthy, M. L., Slomine, B. S., Ding, R., Durbin, D. R., Jaffe, K. M. et al.

(2009). Family burden after traumatic brain injury in children. *Pediatrics*, 123(1), 199-206.

Anderson, V., Brown, S., Newitt, H., & Hoile, H. (2011). Long term outcome from

childhood traumatic brain injury: Intellectual ability, personality and quality of life.

*Neuropsychology*, 25(2), 176-184.

Anderson, V., & Catroppa, C. (2005). Recovery of executive skills following paediatric

traumatic brain injury (TBI): A 2 year follow-up. *Brain Injury*, 19(6), 459-470.

Armstrong, K., & Kerns, K. A. (2002). The assessment of parent needs following paediatric

traumatic brain injury. *Pediatric Rehabilitation*, 5(3), 149-160.

Ball, H., & Howe, J. (2013). How can educational psychologists support the reintegration of

children with an acquired brain injury upon their return to school? *Educational*

*Psychology in Practice*, 29(1), 69-78.

Boylan, A. M., Linden, M., & Alderdice, F. (2009). Interviewing children with acquired

brain injury (ABI). *Journal of Early Childhood Research*, 7(3), 264-282.

Bozic, N., & Morris, S. (2005). Traumatic brain injury in childhood and adolescence: The

role of educational psychology services in promoting effective recovery.

*Educational & Child Psychology*, 22(2), 108-120.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77 – 101.

Brooks, B. M., Rose, F. D., Johnson, D. A., Andrews, T. K., & Gulamali, R. (2003).

Support for children following traumatic brain injury: The views of educational psychologists. *Disability & Rehabilitation*, 25(1), 51-56.

Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Cambridge, MA: Harvard University Press.

Burden, R. L. (1998). Illuminative evaluation. *Educational & Child Psychology*, 15(3), 15 – 24.

Byard, K., Fine, H., & Reed J. (2011). Taking a developmental and systemic perspective on neuropsychological rehabilitation with children with brain injury and their families.

*Clinical Child Psychology & Psychiatry*, 16(2), 165-184.

Calderwood, L. (2003). *Cracked: Recovering after traumatic brain injury*. London:

Jessica Kingsley.

Cameron, R. J. (2006). Educational psychology: The distinctive contribution. *Educational Psychology in Practice*, 22(4), 289-304.

- Carlsson, E., Paterson, B. L., Scott-Findlay, S., Ehnfors, M., & Ehrenberg, A. (2007). Methodological issues in interviews involving people with communication impairments after acquired brain injury. *Qualitative Health Research*, 17(10), 1361-1371.
- Cassidy, J. W. (2009). *Mindstorms: The complete guide for families living with traumatic brain injury*. Massachusetts: Da Capo Press.
- Catroppa, C., & Anderson, V. (2002). Recovery in memory function in the first year following TBI in children. *Brain Injury*, 16(5), 369-384.
- Child Brain Injury Trust. (2003). *I'm not just a head injury on legs*. Oxford: Child Brain Injury Trust.
- Cocks, A. (2006). The ethical maze: Finding an inclusive path towards gaining children's agreement to research participation. *Childhood*, 13(2), 247-266.
- Conradie, L. J., & Ashleigh, S. (2008). Return to work after head injury. *Occupational Health*, 60(4), 43-46.
- Creswell, J. W. (2008). *Research design: Qualitative, quantitative and mixed methods approaches* (3<sup>rd</sup> ed.). California: Sage Publications Ltd.
- Crisp, R. (1993). Personal responses to traumatic brain injury: A qualitative study.

*Disability, Handicap & Society*, 8(4), 393-404.

Crouchman, M. (1990). Head injury-how community paediatricians can help. *Archives of Disease in Childhood*, 65(11), 1286-1287.

Daisley, A., Tams, R., & Kischka, U. (2009). *Head injury: The facts*. New York: Oxford University Press.

Denscombe, M. (2004). *The good research guide for small-scale social research* (2<sup>nd</sup> ed.). Berkshire: Open University Press.

Department for Education. (2013). Draft Special Educational Needs Code of Practice for 0 to 25 years – statutory guidance. Retrieved December 1, 2013 from [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/251839/Draft\\_SEN\\_Code\\_of\\_Practice\\_-\\_statutory\\_guidance.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/251839/Draft_SEN_Code_of_Practice_-_statutory_guidance.pdf)

Department of Health & Department for Education & Skills. (2004). *Acquired Brain Injury*. Retrieved November 17, 2011, from [http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4098553](http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4098553)

Fairclough, P. L. (2002). *Living with brain injury*. London: Jessica Kingsley.

Frank, E. M., Redmond, K. E., Ruediger, T. L., & Scott, W. K. (1997). Preparedness of

educational speech-language pathologists to provide services to students with traumatic brain injury. *Communication Disorders Quarterly*, 18(2), 49-63.

Glang, A., Todis, B., Thomas, C. W., Hood, D., Bedell, G., & Cockrell, J. (2008). Return to school following childhood TBI: Who gets services? *NeuroRehabilitation*, 23, 477-486.

Greig, A., Taylor, J., & MacKay, T. (2007). *Doing research with children* (2<sup>nd</sup> ed.). London: Sage Publications Ltd.

Hawley, C. A., Ward, A. B., Magnay, A. R., & Long, J. (2002). Children's brain injury: A postal follow-up of 525 children from one health region in the UK. *Brain Injury*, 16, 969-985.

Hawley, C. A., Ward, A. B., Long, J., Owen, D. W., & Magnay A. R. (2003). Prevalence of traumatic brain injury amongst children admitted to hospital in one health district: A population-based study. *Injury*, 34(4), 256-260.

Hawley, C. A., Ward, A. B., Magnay, A. R., & Mychalkiw, W. (2004). Return to school after brain injury. *Archives of Disease in Childhood*, 89, 136-142.

Hyder, A. A., Wunderlich, C. A., Puvanachandra, P., Gururaj, G., & Kobusingye, O. C. (2007). The impact of traumatic brain injuries: A global perspective.

*NeuroRehabilitation*, 22, 341-353.

Irwin, L. G., & Johnson, J. (2005). Interviewing young children: Explicating our practices and

dilemmas. *Qualitative Health Research*, 15, 821-831.

Jantz, P. B., & Coulter, G. A. (2007). Child and adolescent traumatic brain injury: Academic,

behavioural, and social consequences in the classroom. *Support for Learning*, 22(2),

84-89.

Jones, A., & Johnson, D. (1994). A study of the educational provision for head-injured

children. *British Journal of Special Education*, 21(3), 113-117.

Lewis, A. (2002). Accessing, through research interviews, the views of children with

difficulties learning. *Support for Learning*, 17(3), 111-116.

Luft, J. (1969). *The Johari window: A graphic model of awareness in interpersonal*

*relations*. New York: NTL Institute Human Relations Training News. Retrieved May

2, 2013, from,

<http://www.library.wisc.edu/edvrc/docs/public/pdfs/LIReadings/JohariWindow.pdf>

McCusker, C. G. (2005). An interacting subsystems approach to understanding and meeting

the needs of children with acquired brain injury. *Educational & Child Psychology*,

22(2), 18-28.

Middleton, J. A. (2001a). Practitioner review: Psychological sequelae of head injury in



- children and adolescents. *Journal of Child Psychology & Psychiatry*, 42(2), 165-180.
- Middleton, J. A. (2001b). Brain injury in children and adolescents. *Advances in Psychiatric Treatment*, 7, 257-265.
- Parlett, M. & Hamilton, D. (1972). *Evaluation as Illumination: A new approach to the study of innovatory programs*. Edinburgh: University of Edinburgh Press.
- Powell, T. (2004). *Head injury: A practical guide* (2<sup>nd</sup> ed.). Oxon: Speechmark Publishing and Headway.
- Rehab Group UK. (2010). *The Brain Injury Handbook*. Retrieved November 17, 2011, from <http://www.rehab.ie/about/braininjuryhandbook.aspx>
- Robson, C. (2011). *Real world research* (3<sup>rd</sup> ed.). Chichester: John Wiley & Sons Ltd.
- Savage, R. C., Depompei, R., Tyler, J., & Lash, M. (2005). Paediatric traumatic brain injury: A review of pertinent issues. *Paediatric rehabilitation*, 8(2), 92-103.
- Savage, R. C., Pearson, S., McDonald, H., Potoczny-Gray, A., & Marchese, N. (2001). After hospital: Working with schools and families to support the long term needs of children with brain injuries. *NeuroRehabilitation*, 16, 49-58.
- Sharp, N. L., Bye, R. A., Llewellyn, W. M., & Cusick, A. (2006). Fitting back in: Adolescents returning to school after severe acquired brain injury. *Disability & Rehabilitation*, 28(12), 767-778.

Smith, J. A. (1995). Semi-structured interviewing and qualitative analysis. In J. A. Smith, R.

Harré & L. V. Langenhove (Eds.), *Rethinking methods in psychology* (pp. 9-26).

London: Sage Publications Ltd.

The Makaton Charity. (2014). *About Makaton*. Retrieved March 17, 2014, from

<https://www.makaton.org/aboutMakaton/default>

Tomlinson, P. (1989). Having it both ways: Hierarchical focusing as research interview

method. *British Educational Research Journal*, 15(2), 155 – 176.

VanderStoep, S.W., & Johnston, D.D. (2010). *Research methods for everyday life: Blending*

*qualitative and quantitative approaches*. San Francisco: John Wiley & Sons.

Walker, S. (2009). *Educational implications for acquired brain injury*. London: Brain and

Spine Foundation, Roald Dahl Foundation and Waterloo Foundation.

Walker, S., & Wicks, B. (2005). *Educating children with acquired brain injury*. Oxon:

David Fulton Publishers.

Wilkinson, Joffe and Yardley (2004). Qualitative data collection: interviews and focus

groups. In D. F. Marks & L. Yardley (Eds.), *Research methods for clinical and health*

*psychology* (pp.39-55). London: Sage Publication.

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## Appendix A: A Detailed Definition of ABI

Further definition and causes of ABI are appended here for completeness. Cassidy (2009) notes the importance to consider the difference in meaning of the terms head injury and brain injury. Many people will experience a head injury during their life time. It would not cause you to lose consciousness but you would likely need a cold compress. In comparison, a brain injury involves damage to the brain itself (bleeding, swelling) whilst the head may appear to be unharmed.

ABI encompasses damage to the brain after the birth and immediate neonatal period. It can be traumatic (TBI) caused by external forces or non-traumatic caused by illness or stroke for example. The term ABI therefore does not include any brain injury present at birth, associated with birth trauma or degenerative in nature (Walker & Wicks, 2005).

TBI caused by external forces can take the form of penetration injuries where the skull is pierced by an object such as a knife or falling onto a sharp object. These injuries are more likely to result in localised areas of damage and therefore specific disability (Powell, 2004). However, injuries can also occur without an object actually penetrating the brain; these are known as impact and deceleration injuries. A person's head (and therefore brain) may hit a hard object through falls, road traffic accidents or assault. This may or may not result in pieces of skull invading a person's brain tissue. During impact a person's brain can be moved or rotated quickly. Damage therefore occurs because of the violent movement of the brain within the skull rather than the presence of a foreign object (Powell; Walker & Wicks, 2005). An ABI is often a series of injuries rather than just one. For example, following the initial impact, there is often further damage in the following minutes due to a

lack of oxygen and then in the days and months following the event, bleeding, swelling and bruising can cause further damage (Powell, 2004).

Non-traumatic brain injuries can be described under the broad term of illness (Walker & Wicks, 2005). Children and young people may have meningitis which results in inflammation of the outer membranes of the brain and spinal cord. Other infections may cause inflammation throughout the brain known as encephalitis. In addition to this bleeding, tumours or abscesses can occupy the space in which healthy brain tissue is meant to be. Secondary complications can occur from treatment of brain based tumours such as chemotherapy and radiotherapy.

As alluded to above, there can be a number of injuries that an initial impact or infection leads to. These range from bruising, bleeding, shearing of tissue, coma, hypoxia (lack of oxygen), swelling, further infection and epilepsy (Walker & Wicks, 2005). Depending on the initial type of injury, damage to the brain can be localised or diffuse and effect different brain pathways and the communication between these (Powell, 2004). The effect of the damage can be unpredictable, particularly in children, “every acquired brain injury results in a unique pattern of strengths and weaknesses, which is frequently complex and unusual and which evolves as a child matures” (Walker & Wicks, 2005, p. 25). The effects of ABI can be divided into broad areas of: physical and sensory, language and communication, attention, information processing, memory, perception and executive functioning. Difficulties in any of these areas are also likely to effect a young person emotionally, socially and behaviourally.

## Appendix B: My Perspective

My perspective is informed by three years of practice in the private and public sectors with adults, children and young people who have experienced ABI:

- Work with adults first introduced me to ABI, disability and applied psychology from a clinical perspective.
- Work as an Assistant EP. During this post, I attended a training course about ABI in children, shadowed the Specialist OT, and also worked alongside an EP on two cases where ABI was a factor in the children's presentation.
- This has led to a two-fold perspective for me in terms of how ABI effects people at different ages and how it is construed, assessed and supported in the differing contexts of clinical and educational psychology.

From my work as a Trainee EP and previous work experience alongside a CP in a brain injury rehabilitation unit for adults, I believe I have a suitable understanding of the impact of brain injury as well as skills in active listening and being sensitive to individual stories. Whilst most of my previous work around brain injury has been with adults, I have experience of working with people who have had significant changes in memory, behaviour and insight due to brain injury and their families who have been faced with a significant period of change and uncertainty. I see this as a period when I was in a professional role, working with people in a vulnerable position. In planning this current research, I recognised that I needed to be sensitive, open and honest in explaining my role as a researcher rather than a Trainee EP who would be offering assessment of a child's SEN. My role within this current research was to explore and uncover issues faced by children with ABI and their families in

terms of schooling since the injury; this was explained to parents in the consent paperwork and in person at the start of interviews in a clear and sensitive way.

I recognised the importance of awareness of how my previous experience could lead to a biased interpretation of findings. I had an understanding of the issues facing people with an ABI. I expected them to have difficulties in communicating and learning and consequently behave in a particular manner. My experience of adults following ABI could be described as the severe end of the spectrum in terms of ABI and its impact. However, the focus of the current research was on mainstream schools and by the very nature of this, mild to moderate injuries resulting in potentially more subtle effects. Therefore I needed to be careful not to project the severe needs of adults I have worked with onto the children and young people identified for the current research. Due to the wide ranging impact of ABI and my previous experiences in a private adult rehabilitation setting in particular, I suspected that the narratives of participants in the current research would be challenge filled. In reality experiences of participants were more positive than I had anticipated they might be.

## **Appendix C: Relevant Training and Learning Experiences**

During years two and three of my doctoral studies, I have actively sought relevant training courses and learning experiences related to childhood ABI. On 6<sup>th</sup> March 2012, 11<sup>th</sup> May 2012 and 6<sup>th</sup> February 2013 I attended study days hosted by the Child Brain Injury Trust and local groups of professionals in the South West and Hampshire. These events stimulated and maintained my interest in the subject. They gave me the opportunity to hear from speakers in the field, what research they were sharing to illustrate their points and whether there was any 'new' information I had not yet identified. I was also able to network with colleagues from different areas and disciplines all with a specific focus on childhood ABI.



## **Appendix D: Literature Review**

**This literature review has been marked SEPARATELY from the examination of this thesis. It is appended here for completeness and to give coherence to the whole thesis.**

### **Childhood Acquired Brain Injury: An Exploratory Study into the Educational Experiences of Children, Their Families and the Professionals who Support Them.**

“I felt like an infant. Of course, I didn’t fully comprehend how this brain injury had changed me; I only sensed that my life would never be the same.” (Calderwood, 2003, p. 9). It would be difficult to ever fully put oneself in the shoes of another person, especially a child, who had experienced a brain injury. Texts like this personal account written by Lynsey Calderwood however, offer some insight into how differently the world is experienced when the brain does not function as it once did. Acquired Brain Injury (ABI) has been described as a hidden disability because of the range of ways in which a person can be affected that may not be visible at a physical level (Sharp, Bye, Llewellyn & Cusick, 2006). Difficulties across social, emotional and cognitive development can impact greatly upon a child’s functioning in a school environment which generally requires quick thinking, focused attention, organisation and an awareness of social rules, especially in the adolescent years. This literature review will present an exploration of the literature in the area of childhood ABI.

The aim is to:

- justify childhood ABI as an area for research particularly in the context of education,
- consider the focus of the existing research and gaps that exist,

- explore how the current research will address these gaps.

The review is divided into sections exploring the following areas. Firstly, details about how the literature search was conducted are given as well as a consideration of how ABI is defined. This is followed by a discussion of why childhood ABI is an important topic to explore, including the estimated prevalence of it within the United Kingdom (UK). Relevant psychological theory will be explored before literature around the impact of ABI for various groups of people is discussed in relation to this theory. The review will conclude by summarising the gaps in the current literature.

### Literature Selection

For the purpose of this literature review, I carried out a comprehensive search of the literature using the following key words in various combinations: acquired brain injury, brain injury, head injury, childhood, paediatric, impact, effects, perceptions, views, parents, teachers, educational psychologists and school. These key words and phrases were entered into the following search engines and databases:

- EBSCO EJS
- JSTOR
- ScienceDirect
- SpringerLink
- Research Pro
- Searches in individual educational psychology related journals such as Educational and Child Psychology

Citation searches were also conducted from papers that were found through the initial searches. Relevant books and book chapters were found by searching the University of Exeter library catalogue, online bookstores and a personal book collection. Government documents were searched through a general internet search engine.

Literature about ABI comes from a variety of disciplines including specific and technical research in the field of health and neuroscience (for example, Kay & Teasdale, 2001).

Therefore, initial sources were chosen using the following criteria: being from the UK or countries with education systems similar to the UK, relevance to the current research questions and focus of the study and accessibility of all the information.

Whilst I had knowledge of ABI and some relevant books in my own collection, this was largely adult related. Therefore, my search of the literature began with finding sources that would introduce me to the specific effects of childhood ABI and the prevalence of it. This started with general sources such as the book by Walker and Wicks (2005) about educating children with ABI and a practitioner review by Middleton (2001a) in the peer reviewed *Journal of Child Psychology and Psychiatry*. I then looked for literature relating to the specific groups of school staff, other professionals (including EPs), parents and the children themselves. Linked to this and two specific journal articles that I had found (Bozic & Morris, 2005; McCuckser, 2005), I then searched for relevant literature around ecological systems theory.

In terms of numbers of results when I searched databases, the phrase 'childhood acquired brain injury' returned 10 results on EBSCO EJS. Of these 10, two were not relevant at all (one was about rats and the other was general abstracts from a journal about medical

genetics) and the others were specific to areas of brain functioning and consequent effects on skills. Another search on EBSCO EJS using the phrase 'effects of brain injury in school' returned 13 results. One of these results were used in this review (Jantz & Coulter, 2007) and the others were judged as not being relevant because they were only very broadly related to ABI and then each had quite a specific focus, for example, effects of ABI in adults and lead poisoning in children. In the 'Neuropsychology' volume of the Educational and Child Psychology journal, there were nine articles. Three related directly to childhood ABI and so were selected for inclusion in the review (Bozic & Morris, 2005; Doherty & McCusker, 2005; McCusker, 2005). Another explored the links between educational psychology and neuropsychology and so this was also selected (Mackay, 2005).

It appears from the literature search that research about childhood ABI, especially in the context of education, is fairly young in its development. Some articles that were found and have been used in this review are influenced by and made up of the professional and expert opinions and experience of the authors (Bowen, Hall, Newby, Walsh, Weatherhead & Yeates, 2009; Savage, Depompei, Tyler & Lash, 2005). However, they did appear in peer-reviewed journals and were felt to be relevant. Building on such research and existing professional experience, will develop knowledge in the field of childhood ABI and add to the already established literature base.

As can be seen from the list of words used in the literature searches, different phrases and terms are used to describe a childhood brain injury. Therefore, it has been important to consider what is meant by ABI.

## How Does the Literature Define ABI?

The terms ABI and traumatic brain injury (TBI) are sometimes used interchangeably in the literature (Bozic & Morris, 2005) and literature from outside of the UK often refers to TBI (Catroppa & Anderson, 2002; D'Amato & Rothlisberg, 1996). The current research will refer to ABI as including any injury that has occurred to the brain after birth that is non-progressive (Rehab Group UK, 2010). ABI can be caused by external force, such as a fall or accident (traumatic) or by illness such as meningitis, tumours and haemorrhage (non-traumatic) (Walker & Wicks, 2005). As can be seen from this definition, there are a variety of reasons for an ABI occurring. This will be explored in more detail in the next section in relation to the relevance of ABI as a topic of study.

## What is the Relevance of This Topic?

Children affected by ABI can experience a variety of outcomes which range from an almost complete recovery to significant and long lasting disability (Byard, Fine & Reed, 2011; Middleton, 2001a; McCusker, 2005). A variety of neural systems can be affected by brain injury and so functioning across a number of domains can be disrupted, including: physical, cognitive, behavioural, social and emotional functioning (Byard et al., 2011; Glang, Todis, Thomas, Hood, Bedell & Cockrell, 2008; Middleton, 2001b). This can impact on a number of areas in the child's life, including their own development and learning as well as those people who support them.

Recent research estimates that in one region in the North of the UK, 280 per 100, 000 children are admitted to hospital each year for 24 hours or more because of a brain injury. Of these, 15% will have experienced a moderate or severe injury (Hawley, Ward, Long,

Owen & Magnay, 2003). This data was based on an already established register of patients and is useful for exploring patterns in the number of children affected and the reasons for brain injury and so could support future planning of health services. The data is however, only based on one region within the UK and wider implementation of recommendations or plans for future practice would be more useful if based on data from a wider geographical spread across the UK. Indeed, accurate statistical information on the prevalence of ABI in children is difficult to obtain (Walker & Wicks, 2005). A report by the House of Commons Select Committee on Health (2001) has advised caution when exploring prevalence statistics in the literature because of the often inadequate data collection systems used in hospitals. Those who have experienced a mild brain injury may not be included in such data but can experience long term consequences (Cicerone et al., 1996) and confusion over definition of ABI may contribute to cases not being recorded (House of Commons Select Committee on Health). Whilst it remains challenging to report on exact figures, there is consistent agreement within the literature that ABI is a significant issue which has immediate, long-lasting and variable consequences for the children that it affects (Anderson, Brown, Newitt & Hoile, 2011; Brooks, Rose, Johnson, Andrews & Gulamali, 2003; Bowen et al. 2009; Glang et al., 2008; Hyder, Wunderlich, Puvanachandra, Gururaj & Kobusimgye, 2009; Jones & Johnson, 1994; Middleton, 2001a).

The United States of America (USA) recognises ABI as an SEN (Russell, 1993). It has been described by some American researchers as a low incidence special educational need (SEN) (Glang et al., 2008). According to a report by the UK Department for Education and Skills (DfES, 2006), a low incidence SEN describes a need that occurs less frequently and may require a more specialist response than other needs. However, ABI is not stated in the UK

SEN Code of Practice (DfES, 2001). This is despite disparity across the group in their ability to reach potential because of the range of effects following ABI and the unique characteristics of it (Rees & Skidmore, 2008). In 2004, best practice guidance was issued by the Department of Health (DoH) and DfES for professionals from a range of backgrounds to provide an example of the processes involved in supporting a child with ABI. The Educational Psychologist (EP) is highlighted as being important at three stages in the document: follow up care and provision, early provision of education needs and during the secondary school period. The DoH and DfES guidance states that “close liaison between educational and clinical neuropsychologist is critical throughout the entire process” (p. 22). However, it would appear that little is known within the literature about whether this actually occurs. For example, Bozic and Morris (2005) reported that in the experience of the EPs they surveyed, it was unusual for specialist colleagues such as neuropsychologists to be involved in school based consultation about children with ABI.

Indeed, Mackay (2005) has reported that there is very little literature exploring relationships between educational psychology and neuropsychology, although he argued that clinical neuropsychology is central to educational psychology. MacKay discussed the similarities between clinical psychology, educational psychology and clinical neuropsychology, as well as the differences in their main emphasis for applied work and research. In terms of brain, development and context, educational psychology’s weakest area is that of the brain. MacKay argued that relationships between the brain and behaviour have largely been a small part of initial educational psychology training courses. On the other hand, he notes that context is strongly emphasised in educational psychology. This is especially so through the increasing use of consultation as a model of service delivery through which joint

problem solving can take place with those who know the child best across a variety of environments (Wagner, 1995). It would appear from the Bozic and Morris (2005) research that EPs remain quite unsupported in terms of 'the brain' if they are the main point of contact for schools following childhood ABI and other colleagues do not become involved.

### **An Ecological Systems Perspective on ABI**

ABI and research about it needs to be considered in terms of models of disability. According to the medical model, disability occurs due to within child factors. Often, terminology from the medical profession is used to describe people and their disabilities with the aim of treating or curing deficits (Hodkinson & Vickerman, 2009). Under this model, SEN arises from psychological, neurological or physiological deficits within the person (Skidmore, 2004). An understanding of the medical model and the organic damage experienced by children with ABI is needed, especially in the initial stages of treatment when there is need for vital intervention from the health sector. Following this life saving and necessary medical intervention, I think it is important that educational professionals take account of the role of context in a child's ABI and future recovery. As identified by Mackay (2005), this would include EPs due to the strong emphasis of context within educational psychology.

Therefore, I believe that in order to understand ways in which children with ABI can best be supported in education; a consideration of factors from within the contexts around them, such as their home, school and community is needed. Pertinent to this is ecological systems theory which has highlighted the importance of interactions between systems (Bronfenbrenner, 1979). Bronfenbrenner proposed a broader approach to investigating and understanding human development. This includes consideration of various interacting



systems which influence a child's development: the microsystem, mesosystem, exosystem, macrosystem and chronosystem. According to Bronfenbrenner, the ecological environment encompasses the developing child, the environment and the interaction between the two. Cicchetti and Lynch (1993) developed the work of Bronfenbrenner through an ecological-transactional model in their literature about children and violence. The use of an ecological-transactional model is useful in exploring how different environments influence a child's development (Cicchetti & Toth, 1997). Similarly to Bronfenbrenner, Cicchetti and Lynch suggested that different systems within the child's environment interact with each other over time thus influencing their development. Changes in the roles of those within a setting can be important for development because expectations for behaviour change (Bronfenbrenner). An example of a shift in roles within a family and in a school context is the occurrence of childhood ABI.

This theory is relevant to the current literature review because it promotes consideration of the effect of different contexts on the child with ABI as well as how the consequences of the ABI may affect other people across those contexts. Indeed, McCusker (2005) argued that when considering children with ABI, a simple medical model is insufficient because of the various complex systems they interact with. McCusker suggested that psychological formulation of a child's needs should include consideration of potential interacting factors in their environment. This is because in restricting assessment of children with ABI to any one level, alternative influences on their development or functioning may be missed. McCusker argued that there is little or no research about how the organisation, teaching methods, beliefs and culture of a school and teachers effect the adjustment of children with ABI. Focusing too much on a medical model approach after the initial lifesaving and necessary

medical intervention could ignore other important factors in a child's long term recovery and rehabilitation. EPs are particularly well placed and skilled to support those working with a child with ABI to consider the various interacting systems and factors around a child, as context is highly emphasised in their discipline (Mackay, 2005).

### **What is Known About the Impact of ABI?**

The long-term consequences of ABI facing those children affected, continues to be a poorly understood area in the literature (Anderson et al., 2011). The effects of ABI can be many and varied. The consequent difficulties facing children impact upon their ability to interact with their environment successfully, thus leading to delayed or impaired acquisition of skills in the academic and social domains (Anderson et al.). The consequences of an ABI may be less obvious in the early stages of a child's recovery and rehabilitation, only becoming noticed over time when many physical difficulties have recovered and people around the child may see the ABI as a distant and unrelated event (Frampton, 2004; Jones & Johnson, 1994; Lord-Maes & Obrzut, 1996; Middleton, 2005).

Despite the literature that reports that the effects of ABI are misunderstood and underestimated, it has been reported that many children who have experienced ABI are likely to be in mainstream education (Limond, Dorris & McMillan, 2009). It is often schools and families who provide long term support and rehabilitation for children with ABI rather than medical services or specialist teams. It has been proposed that "families and schools are pivotal in the long term outcome of children" (Savage, Pearson, McDonald, Potoczny-Gray & Marchese, 2001, p. 49). Similarly, Savage et al. (2005) suggested that "educational

systems are often the best services to address the needs of these children, especially the cognitive, communication and behavioural challenges” (p. 102).

In reference to ecological systems theory (Bronfenbrenner, 1979), the literature about the impact of ABI has been divided into thematic sections with reference to different groups of people and childhood ABI. The role of external agencies and impact of ABI in relation to the knowledge and experience of professionals will now be explored.

### **The Role of External Agencies**

Literature about the role of external agencies in supporting children with ABI in a school context is limited. Two UK based studies focused on the role of the EP in particular have been identified.

Firstly, Brooks et al. (2003) carried out a study to explore whether the training and experience of EPs makes them aware that young children in particular are vulnerable to the effects of an ABI. EPs were asked to rate case histories on various scales including what they thought would be the additional needs of the child’s family and how long injury consequences would last; 158 EPs completed the rating scales. Using quantitative data analysis, Brooks et al. found that EPs rated children with severe ABI and children who had sustained ABI at a younger age as requiring additional and long-term support. Brooks et al. concluded that their findings suggest that children who have sustained an ABI are in receipt of the additional educational support that they require. This is a sweeping conclusion and generalisation to make based on what the authors’ admit was a low response rate from EPs. The authors also failed to ask other key people involved in the education of children with ABI such as the children themselves and their parents. Secondly, the methods used did not

allow the thoughts and experiences of EPs to be revealed. For these reasons, I feel that this study adds little to our current understanding of the schooling experiences of children with ABI or the issues that face the professionals such as EPs in supporting them.

Secondly, Bozic and Morris (2005) explored the role of educational psychology services in the promotion of effective recovery following childhood ABI. It was found that in approximately 80% of cases, initial educational psychology training courses provided very little if any preparation for this area of professional practice. Bozic and Morris concluded that there is a need for EPs to develop knowledge and skills in relation to working with children who have ABI. This is especially important because the research also found that it is often the EP who is the professional most called upon for support in planning a child's education post ABI. It was recognised by Bozic and Morris that the views of other key stakeholders such as the children, teachers and parents were not included in their study.

In terms of other agencies, a small amount of research has been found concerning Paediatric Health and Speech and Language Services. Research from an occupational therapy perspective has been found although it is noted that this is in relation to adult ABI and their return to work (Conradie & Ashleigh, 2008) rather than children.

There has been some discussion about the assessments used with children with ABI by the USA equivalent to Speech and Language Therapists (Russell, 1993). Frank, Redmond, Ruediger and Scott (1997) used questionnaires to survey educational speech-language pathologists in the USA to explore their knowledge about childhood ABI and their preparedness to work with these children. The results suggested speech-language pathologists did not feel highly confident in working with children with ABI and that

interaction between rehabilitation teams and multidisciplinary professionals who work in schools was not high.

According to Crouchman (1990) however, educational provision must be made for the child with ABI as soon as they are well enough to attend school. Crouchman suggested that paediatric health services need to be aware of educational provision so as to be able to liaise with and advise both families and education authorities. This is a suggestion of what should happen and there does not seem to be any information within existing literature about whether it does.

If little is known about the impact of ABI in relation to the role of external agencies, what, if any literature exists to develop our understanding about the school context and ABI? The next section will explore this.

### **The School Context**

The school context for the child with ABI includes taking on demanding learning tasks and interacting with teachers and peers in formal and social situations. The potential cognitive difficulties facing a child such as changes in attention (Daisley, Tams & Kischka, 2009), memory (Catroppa & Anderson, 2002), information processing speed (Walker, 2009) and executive functioning (Anderson & Catroppa, 2005; Powell, 2004) can make it very difficult for children to make sense and keep track of the varied information in their social and learning environments. Therefore it is important to review the literature which explores the impact of ABI in relation to the school context in particular.

Firstly, Crothers, Linden and Kennedy (2007) were interested in exploring the attitudes of children towards a fictional peer with an ABI. A vignette was used to describe the change in a boy following ABI and the children were asked to complete a rating scale to explore how likely it would be that they would befriend a child like this. They found that girls were more likely to show a willingness to befriend a peer with ABI although by secondary school, boys became more willing to do so too. This study had a reasonable sample size (100) and included children of primary and secondary age. The rating scale the authors used has also been measured as having good internal consistency (see Crothers et al. p. 49). In terms of the school context, this study is relevant although only in the broader sense of trying to establish how others react to a child with ABI. As rightly acknowledged by the authors, there is now a need to more fully explore the social experiences of children with ABI. This would complement the existing study by seeking the views of the children with ABI and comparing it to the responses of peers.

Teachers have been identified as people who spend the greatest amount of time with children in a school setting (Jantz & Coulter, 2007). However, it has been suggested that the impact of ABI in children is underestimated by many countries and remains an area that is misunderstood by professionals (Savage et al., 2005). Difficulties associated with ABI are often not well recognised by schools, representing a significant area to develop knowledge of (Walker & Wicks, 2005). Research in the area of school context and ABI is limited, although what literature there is suggests that many teachers do not receive any training in relation to ABI and the impact of it (Jones & Johnson, 1994). Targeted education of teachers regarding the effects of ABI has been deemed important in developing improved support for young people during their transition and settling period at school following ABI (Sharp et al.,

2006). Sharp et al. came to these conclusions based on interviews with Australian adolescents and their parents. This needs to be noted when considering the relevance of these findings and generalisability to the UK education system. However, a UK based study has also suggested that future research in the area of paediatric ABI needs to focus on the training of teachers in order to prepare them for educating a child with these needs (Hawley, 2005). This suggests that this is an area of importance in the UK and abroad.

Other research has been conducted in the UK to explore children's performance in school after ABI (Hawley, Ward, Magnay & Mychalkiw, 2004). It was found that teachers reported the children to have problems with their school work, memory and attention. However, approximately one third of the 67 teachers who took part in the research did not know that a child had a brain injury. The authors concluded that teachers were rarely aware of the possible long-lasting effects of ABI (Hawley et al.). It has also been reported by Hawley, Ward, Magnay and Long (2002) that when an ABI had invisible effects, few children were offered help whereas teachers made special arrangements for children who had visible physical injuries. Therefore, the authors recommended that teachers should be provided with a list of the possible cognitive and behavioural consequences of ABI.

It appears that research involving teachers has focused more on the child's difficulties and functioning since ABI as well as highlighting how little teachers know about ABI in general. This has been instead of exploring views about teachers' experience of supporting a child with ABI, who and what have helped and what challenges there have been. I believe such information would complement the existing literature. Closer to the child than school staff and an essential source of support is the family. The next section will explore what is known in the literature about the impact of ABI on families, their views and experiences.

## Impact on Family

The impact of ABI on a child's family is long-term, often extending past the formal rehabilitation stage when professional support significantly decreases (Byard et al., 2011; Doherty & McCusker, 2005). The long term family stress and child adjustment difficulties may require psychological support on a long-term basis (Anderson et al., 2011) and it has been suggested that "the relationship between injury and family function seems to be bi-directional" (Byard et al., p. 167). The EP is a well-placed professional for providing this support in terms of their links with schools, family and the community.

As has been discussed, the effects of an ABI can range from mild to severe but the specific effects of damage varies from person to person. Florian and Katz (1991) have suggested that the reaction of family members to a child's brain injury can also vary. The families of individuals who have experienced ABI have been described as the victims of trauma by these researchers and it is for this reason that families often require a high level of support from services. The holistic nature of the effects of ABI is often difficult for families to cope with and therefore effective support needs to take a holistic approach too (Florian & Katz). Indeed, Mackay (2006) argued that the EP is in a unique position to, in collaboration with other professionals, provide a holistic service to children and young people across a number of settings. Two studies which included parents of children with ABI as participants will now be explored.

Armstrong and Kerns (2002) were interested in the needs of parents following childhood ABI. The Canadian based research collected quantitative data through the use of questionnaires with parents of children with ABI, a year after injury. The parents of children



with orthopaedic injuries and diabetes were included as control groups. The researchers found that parents of children with ABI reported a greater number of important needs such as needing teachers to understand their child's problems, compared to the orthopaedic control group. However, it was also found that the majority of these needs remained unmet even up to three years post injury. The need for information over time was highlighted as being important for parents of children with ABI. These authors were interested in parental views because of the limited amount of literature exploring the needs of parents in the later stages of a child's recovery following ABI. This is despite, they argue, this being an important time when access to specialist services typically decreases but parental and family needs remain. The use of quantitative measures only may have missed opportunities to capture rich data in terms of parental perceptions and detail about how things could be better for them and what support they would like.

Family burden following childhood ABI has been explored in an American context (Aitken et al., 2009). Questionnaires and rating scales were used to identify caregivers' stress and worry and their child's quality of life since ABI. It was found that caregivers reported general worry and specific concerns about their child's physical functioning, emotional health and learning skills as well as financial struggle for the family. Caregivers were more likely to report burden when their child was in poorer health and their needs had been unmet. The researchers suggested that improved identification of families and provision of services is needed in supporting the reduction of family burden after childhood ABI. It should be noted that this study along with the work of Florian and Katz (1991) and Armstrong and Kerns (2002) are based internationally and therefore relevance to the UK context may be reduced.

This section has explored literature which has been concerned with the impact of ABI upon parents and families. The literature reviewed here has taken a quantitative perspective, using rating scales and questionnaires. A qualitative approach would be a useful complement to this existing literature so as to develop a more detailed understanding of the opinions and views of these parents. The next section will focus on the views of children with ABI.

### Views of Children

Overall, very few studies have reported the experiences of living with ABI by someone who has experienced it first-hand (Crisp, 1993). Instead, literature often reports data of a quantitative nature, neglecting to incorporate the experiences and opinions of children personally effected (Boylan, Linden & Alderdice 2009). Whilst qualitative methods have been used to explore the views of adults following brain injury (Crisp) only one study has been identified that includes the views of children with ABI.

Sharp et al. (2006) carried out a total of 30 interviews with eight adolescents and their families over a two year period in an Australian context. The aim of this was to develop understanding about the influence of support offered at the point of return to school. Using semi-structured interviews, the researchers collected data to explore the adaptation of the young people and their families. It was found that there were two critical phases to describe the experience of the participants as they returned to school: organisation of the school return and then being back at school. It was also reported that the young people faced the challenge of fitting back in on their return to school and this was helped or hindered according to a number of factors, such as organisation of the school return and

support from parents and teachers. This study is important because it has included young people affected by ABI directly as participants and explored their views through qualitative data collection and analysis techniques. Research of a similar nature has not been identified in a UK context and so this is currently a gap in the literature because of the different education system and services available to children and young people affected by ABI in the UK. It would also be useful to seek the views of younger children in future research.

Boylan et al. (2009) explored the challenges involved in interviewing children with ABI. Whilst they gave examples of interviews with children to illustrate their points, their article primarily addressed the challenges of interviewing rather than analysing data collected through interviews with children. Prior to the publication of this paper by Boylan et al., The Child Brain Injury Trust (2003) carried out some research using interviews to discover the key issues facing children and young people who have ABI. Whilst the charity have a good awareness of the issues facing children with ABI and therefore the challenges of interviewing them, the piece of work was carried out for a specific purpose and was not published as a research article by the charity.

There have been books published by both adults (Fairclough, 2002) and young people (Calderwood, 2003) about their personal experiences of ABI. Whilst this type of literature provides a unique insight into the impact of ABI - "no one knew the extent of my injuries, and I didn't realise the severity of my memory loss, until after I returned to school" (Calderwood, p. 67) - it is not specifically related to schooling experiences or the views and perceptions of other key people.

It is recognised from the literature review that including children with ABI in qualitative research potentially involves complex issues and consideration of the child's difficulties since injury (Boylan et al., 2009; Carlsson, Paterson, Scott-Findlay, Ehnfors & Ehrenberg, 2007). However, it is arguable that the current lack of information outweighs the challenges.

These sections have discussed the literature relevant to different groups of people across the child's system. Sharp et al. (2006) interviewed adolescents and parents as part of the same study. However, the views and experiences of all of the groups discussed above, including a range of external agency professionals who support children with ABI have not been considered within one piece of research. Consequently, the literature reviewed here adds to knowledge only in separate layers of a child's ecological system rather than exploring multiple aspects and interactions across the systems.

### **What Gaps in the Literature Exist and how will the Current Research Address These?**

This literature review has shown that childhood ABI is a significant issue for the children, their parents and the professionals who are tasked with supporting them. Whilst existing literature has discussed the effects of an ABI and the consequences for family, it appears that the impact of ABI is frequently misunderstood by those closely involved in the long term rehabilitation process. Despite being the long term provider of support and rehabilitation, the school context appears to be largely missed from existing literature.

What literature there is claiming to have sought the views of those involved, uses predominantly quantitative data collection and analysis techniques characterised by questionnaires and rating scales. Indeed, Crothers et al. (2007) have highlighted that there is very little known about the school experiences of children with ABI. They also advise that

future research exploring this area should be approached from a qualitative perspective to gain an understanding of how the school experiences of children with ABI differ from their peers and what concerns this may include.

This review of relevant literature establishes the strong need for further research into how children and young people experience school following ABI. Linked to this it calls for more research into the experience of families and the role and experiences of professionals who support these children. In the green paper exploring new approaches to SEN, the Department for Education (2011) reported that children with SEN feel frustrated by the lack of correct support from their schools and other services. Due to ABI not being recognised as an SEN in the UK and the general lack of awareness and understanding, this may be even more pertinent for children with ABI. The child with ABI cannot be viewed in isolation, they are part of an interdependent network and therefore further research to explore the experiences of their parents and professionals who work with them will gain a holistic understanding of the different views and needs of each group (Boylan et al., 2009).

My research study aims to address these gaps in the literature and develop knowledge within this particular field. Such knowledge will be of interest to a) children and young people who have ABI b) their parents c) school staff and d) professionals from external agencies who work with them. The findings will be particularly interesting to EPs who, given their training, knowledge, roles within local authorities and understanding of the school context, have a key part to play in overseeing the education of this group of children.

Word Count: 6014

## References for Literature Review

Aitken, M. E., McCarthy, M. L., Slomine, B. S., Ding, R., Durbin, D. R., Jaffe, K. M. et al.

(2009). Family burden after traumatic brain injury in children. *Pediatrics*, 123(1), 199-206.

Anderson, V., Brown, S., Newitt, H., & Hoile, H. (2011). Long term outcome from

childhood traumatic brain injury: Intellectual ability, personality and quality of life. *Neuropsychology*, 25(2), 176-184.

Anderson, V., & Catroppa, C. (2005). Recovery of executive skills following paediatric

traumatic brain injury (TBI): A 2 year follow-up. *Brain Injury*, 19(6), 459-470.

Armstrong, K., & Kerns, K. A. (2002). The assessment of parent needs following paediatric

traumatic brain injury. *Pediatric Rehabilitation*, 5(3), 149-160.

Bowen, C., Hall, T., Newby, G., Walsh, B., Weatherhead, S., & Yeates, G. (2009).

The impact of brain injury on relationships across the lifespan and across school, family and work contexts. *Human Systems: The Journal of Therapy, Consultation & Training*, 20(1), 62-77.

Boylan, A. M., Linden, M., & Alderdice, F. (2009). Interviewing children with acquired

brain injury (ABI). *Journal of Early Childhood Research*, 7(3), 264-282.

Bozic, N., & Morris, S. (2005). Traumatic brain injury in childhood and adolescence: The role of educational psychology services in promoting effective recovery.

*Educational & Child Psychology, 22*(2), 108-120.

Brooks, B. M., Rose, F. D., Johnson, D. A., Andrews, T. K., & Gulamali, R. (2003).

Support for children following traumatic brain injury: The views of educational psychologists. *Disability & Rehabilitation, 25*(1), 51-56.

Bronfenbrenner, U. (1979). *The ecology of human development: experiments by nature and design*. Cambridge, MA: Harvard University Press

Byard, K., Fine, H., & Reed J. (2011). Taking a developmental and systemic perspective on neuropsychological rehabilitation with children with brain injury and their families.

*Clinical Child Psychology & Psychiatry, 16*(2), 165-184.

Calderwood, L. (2003). *Cracked: Recovering after traumatic brain injury*. London:

Jessica Kingsley.

Carlsson, E., Paterson, B. L., Scott-Findlay, S., Ehnfors, M., & Ehrenberg, A. (2007).

Methodological issues in interviews involving people with communication

impairments after acquired brain injury. *Qualitative Health Research, 17*(10),

1361-1371.

Catroppa, C., & Anderson, V. (2002). Recovery in memory function in the first year following TBI in children. *Brain Injury*, 16(5), 369-384.

Child Brain Injury Trust. (2003). *I'm not just a head injury on legs*. Oxford: Child Brain Injury Trust.

Cicchetti, D., & Lynch, M. (1993). Toward an ecological/transactional model of community violence and child maltreatment: Consequences for children's development. *Psychiatry*, 56, 96-118.

Cicchetti, D., & Toth, S. L. (1997). Transactional ecological systems in developmental psychopathology. In J. A. Burack, D. Cicchetti & J. R. Weisz (Eds.), *Developmental psychopathology: perspectives on adjustment, risk and disorder* (pp. 317-349). New York: Cambridge University Press.

Cicerone, K., Smith, L. C., Ellmo, W., Mangel H. R., Nelson, P., Chase, R. F., et al. (1996). Neuropsychological rehabilitation of mild traumatic brain injury. *Brain Injury*, 10(4), 277-286.

Conradie, L. J., & Ashleigh, S. (2008). Return to work after head injury. *Occupational Health*, 60(4), 43-46.

Crisp, R. (1993). Personal responses to traumatic brain injury: A qualitative study.



*Disability, Handicap & Society*, 8(4), 393-404.

Crothers, L. R., Linden, M. A., & Kennedy, N. (2007). Attitudes of children towards peers with acquired brain injury (ABI). *Brain Injury*, 21(1), 47-52.

Crouchman, M. (1990). Head injury-how community paediatricians can help. *Archives of Disease in Childhood*, 65(11), 1286-1287

Daisley, A., Tams, R., & Kischka, U. (2009). *Head injury: the facts*. New York: Oxford University Press.

D'Amato, R. C., & Rothlisberg, B. A. (1996). How education should respond to students with traumatic brain injury. *Journal of Learning Disabilities*, 29(6), 670-683.

Department for Education. (2011). *Support and aspiration: a new approach to special educational needs and disability – a consultation*. Retrieved May 1, 2011, from <https://www.education.gov.uk/publications/standard/publicationDetail/Page1/CM%208027>

Department for Education & Skills. (2001). *Special educational needs – code of practice*. London: DfES.

Department for Education & Skills. (2006). *National audit of support services and provision for children with low incidence needs*. London: DfES. Retrieved May 8, 2011, from

<https://www.education.gov.uk/publications/standard/publicationdetail/page1/RR72>

9

Department of Health & Department for Education & Skills. (2004). *Acquired brain injury*.

Retrieved November 17, 2011, from

[http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4098](http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4098)

553

Doherty, N. N., & McCusker, C. G. (2005). Assessment of functional and psychosocial

outcomes in children four years post head injury. *Educational & Child Psychology*,

22(2), 29-38.

Fairclough, P. L. (2002). *Living with brain injury*. London: Jessica Kingsley.

Florian, V., & Katz, S. (1991). The other victims of traumatic brain injury: Consequences

for family members. *Neuropsychology*, 5(4), 267-279.

Frampton, I. (2004). Research in paediatric neuropsychology-past, present and future.

*Pediatric Rehabilitation*, 7(1), 31-26.

Frank, E. M., Redmond, K. E., Ruediger, T. L., & Scott, W. K. (1997). Preparedness of

educational speech-language pathologists to provide services to students with

traumatic brain injury. *Communication Disorders Quarterly*, 18(2), 49-63.

- Glang, A., Todis, B., Thomas, C. W., Hood, D., Bedell, G., & Cockrell, J. (2008). Return to school following childhood TBI: Who gets services? *NeuroRehabilitation*, 23, 477-486.
- Hawley, C. A. (2005). Saint or sinner: Teacher perceptions of a child with traumatic brain injury. *Pediatric Rehabilitation*, 8(2), 117-129.
- Hawley, C. A., Ward, A. B., Magnay, A. R., & Long, J. (2002). Children's brain injury: A postal follow-up of 525 children from one health region in the UK. *Brain Injury*, 16, 969-985.
- Hawley, C. A., Ward, A. B., Long, J., Owen, D. W., & Magnay A. R. (2003). Prevalence of traumatic brain injury amongst children admitted to hospital in one health district: A population-based study. *Injury*, 34(4), 256-260.
- Hawley, C. A., Ward, A. B., Magnay, A. R., & Mychalkiw, W. (2004). Return to school after brain injury. *Archives of Disease in Childhood*, 89, 136-142.
- Hodkinson, A., & Vickerman, P. (2009). *Key issues in special educational needs and inclusion*. London: Sage Publications.
- House of Commons Select Committee on Health. (2001). *Third report: Head injury rehabilitation*. Retrieved November 13, 2011, from

Hyder, A. A., Wunderlich, C. A., Puvanachandra, P., Gururaj, G., & Kobusingye, O. C.

(2007). The impact of traumatic brain injuries: A global perspective.

*NeuroRehabilitation*, 22, 341-353.

Jantz, P. B., & Coulter, G. A. (2007). Child and adolescent traumatic brain injury: Academic, behavioural, and social consequences in the classroom. *Support for Learning*, 22(2), 84-89.

Jones, A., & Johnson, D. (1994). A study of the educational provision for head-injured children. *British Journal of Special Education*, 21(3), 113-117.

Kay, A., & Teasdale, G. (2001). Head injury in the United Kingdom. *World Journal of Surgery*, 25, 1210-1220.

Limond, J., Dorris, L., & McMillan, T. M. (2009). Quality of life in children with acquired brain injury: Parent perspectives 1-5 years after injury. *Brain Injury*, 23(7-8), 617-622.

Lord-Maes, J., & Obrzut, J. E. (1996). Neuropsychological consequences of traumatic brain injury in children and adolescents. *Journal of Learning Disabilities*, 29(6), 609-617.

- Mackay, T. (2005). The relationship of educational psychology and clinical neuropsychology. *Educational & Child Psychology*, 22(2), 7-17.
- Mackay, T. (2006). The educational psychologist as community psychologist: Holistic child psychology across home, school and community. *Educational & Child Psychology*, 23(1), 7-15.
- McCusker, C. G. (2005). An interacting subsystems approach to understanding and meeting the needs of children with acquired brain injury. *Educational & Child Psychology*, 22(2), 18-28.
- Middleton, J. A. (2001a). Practitioner review: Psychological sequelae of head injury in children and adolescents. *Journal of Child Psychology & Psychiatry*, 42(2), 165-180.
- Middleton, J. A. (2001b). Brain injury in children and adolescents. *Advances in Psychiatric Treatment*, 7, 257-265.
- Middleton, J. A. (2005). Acquired brain injury. *Psychiatry*, 4(7), 61-64.
- Powell, T. (2004). *Head injury: A practical guide* (2<sup>nd</sup> ed.). Oxon: Speechmark Publishing and Headway.
- Rees, S. A., & Skidmore, D. (2008). The classical classroom: enhancing learning for pupils with acquired brain injury (ABI). *Journal of Research in Special Educational Needs*,

8(2), 88-95.

Rehab Group UK. (2010). *The brain injury handbook*. Retrieved November 17, 2011,

from <http://www.rehab.ie/about/braininjuryhandbook.aspx>

Russell, N. K., (1993) Educational considerations in traumatic brain injury: The role of the

speech-language pathologist. *Language, Speech & Hearing Services in Schools*,

24, 67-75.

Savage, R. C., Depompei, R., Tyler, J., & Lash, M. (2005). Paediatric traumatic brain

injury: A review of pertinent issues. *Paediatric rehabilitation*, 8(2), 92-103.

Savage, R. C., Pearson, S., McDonald, H., Potoczny-Gray, A., & Marchese, N. (2001).

After hospital: Working with schools and families to support the long term needs of

children with brain injuries. *NeuroRehabilitation*, 16, 49-58.

Sharp, N. L., Bye, R. A., Llewellyn, W. M., & Cusick, A. (2006). Fitting back in:

Adolescents returning to school after severe acquired brain injury. *Disability &*

*Rehabilitation*, 28(12), 767-778.

Skidmore, D. (2004). *Inclusion: the dynamic of school development*. Maidenhead: Open

University Press.

Wagner, P. (1995). *School consultation: A handbook for practising educational*

*psychologists*. Kensington and Chelsea EPCS.

Walker, S. (2009). *Educational implications for acquired brain injury*. London: Brain and

Spine Foundation, Roald Dahl Foundation and Waterloo Foundation.

Walker, S., & Wicks, B. (2005). *Educating children with acquired brain injury*. Oxon:

David Fulton Publishers.

## Appendix E: Additional Information About Participants For Papers One and Two

### Details of the ABI Sustained by Youth Participants Paper One

<u>Child Name &amp; Age</u>	<u>Reason for ABI</u>	<u>Years Since Injury</u>	<u>Known to EP</u> <u>Service</u>
Beth 17 years	Meningitis	5	No
Billy 9 years	Tumour	2	No
Cassie 17 years	Meningitis	5	Yes
Jack 7 years	Fall	2	No
Mike 16 years	Road traffic collision	4	Yes
Owen 13 years	Fall	5	Yes

None of the young people had existing medical conditions or SEN prior to their ABI.

All of the young people and their parents were interviewed in their homes with the exception of Billy and his Mother who were interviewed at the school.



## Details of Paper Two Participants

	<u>Professional Group</u>	<u>Employer</u>	<u>Number of Years in Role</u>
External Agency	Harriet CP	NHS Trust	6
	Emily EOTAS Tutor	Local Authority	15
	David EP	Local Authority	10
	Miranda EP	Local Authority	9
	Sadie Nurse	NHS Trust	15
	Nicole Paediatrician	NHS Trust	20+
School Based	Anne Specialist OT	NHS Trust and self employed	28
	Carol Primary SENCO	Local Authority Primary School	4
	Stephanie Primary SENCO	Local Authority Primary School	7
	Claire Primary Teacher	Local Authority Primary School	13
	Kelly Primary Teacher	Local Authority Primary School	12
	Emma Secondary TA	Local Authority Secondary School	6
	Kay Secondary SENCO	Local Authority Secondary School	1
	Jane Secondary SENCO	Local Authority Secondary School	6

<u>Professional Group</u>		<u>Location of Interview</u>
External Agency	Harriet CP	Place of work - hospital office
	Emily EOTAS Tutor	Place of work - hospital classroom
	David EP	Place of work - local authority office
	Miranda EP	Place of work - local authority office
	Sadie Nurse	Place of work - hospital office
	Nicole Paediatrician	Place of work - hospital office
	Anne Specialist OT	Place of work - private office
School Based	Carol Primary SENCO	Place of work - school
	Stephanie Primary	Place of work - school
	SENCO	
	Claire Primary Teacher	Place of work - school
	Kelly Primary Teacher	Place of work - school
	Emma Secondary TA	Place of work - school
	Kay Secondary SENCO	Place of work - school
	Jane Secondary SENCO	Place of work – school

## Appendix F: Interview Schedules

Interview schedules for paper one and two were devised using hierarchical focusing. This method 'seeks to elicit the interviewee's construals with a minimum of framing and uses a hierarchical interview agenda to raise topics only as necessary" (Tomlinson, 1989, p. 165). Tomlinson suggests a five step process for carrying out hierarchical focusing: explore the area in question in a hierarchical way; decide on a research focus and which aspects of the topic views will be elicited about; visually portray a hierarchical agenda of questions; carry out the interview in a non-directive style; and make transcripts from voice recordings. This appendix outlines the broad themes I have identified from existing literature, my reflections on this for which areas to cover in the interview questions and then tables showing the interview schedules with general and prompt questions.

### Themes from the Literature Review

Varied, subtle and long-lasting consequences of ABI (Bozic & Morris, 2005; Hawley, Ward, Magnay & Long, 2002 Middleton 2001b; Middleton, 2005)

Parents and schools provide long term rehabilitation for these children (Savage, Pearson, McDonald, Potoczny-Gray & Marchese, 2001).

Many children with ABI return to a mainstream school, however, research suggests that it is poorly understood by teachers (Walker & Wicks, 2005).

Parents experience long term stress and as the providers of long term care and rehabilitation worries can range from specific concerns about their child's functioning to wider concerns about financial stability (Aitken et al., 2009). Compared to other groups of parents, parents of children with ABI report (through quantitative measures) a greater need for teachers to

understand their child's difficulties (Armstrong & Kerns, 2002). However, they are also the parents who report most unmet needs. No literature has been found which asks parents about their experiences.

*Reflection on literature: It seems that school may be a good focus within which to question, given that alongside parents, schools provide long term rehabilitation and teacher's understanding of a child's difficulties has been reported as an important area. It would be useful to find out from parents how they describe the school experience since ABI, who has supported them? What have been the challenges or concerns?*

The majority of research in the field of ABI has been quantitative and has also failed to ask children who have first-hand experience of living with the effects of an ABI (Boylan, Linden & Alderdice, 2009; Crisp, 1993). Crothers, Linden and Kennedy (2007) highlighted that very little is known about the schooling experiences of children with ABI and suggest that more should be done to explore this through qualitative approaches.

*Reflection on literature: Therefore, it would be interesting to ask the children: what is good about school? What is difficult? Who has helped you? Is there anything that could be better?*

Literature about the role of external agencies is limited. Educational Psychologists (EP) are reported to not know enough about ABI and yet are the most frequently called upon professionals to support a child's education post ABI (Bozic & Morris, 2005).

*Reflection on literature: It would be interesting to ask EPs and their colleagues from other external agencies (OT, CP etc.) how have they reacted to their experience of supporting a child with ABI? Who else was involved? Who was it most useful to work with? What are the challenges? How could service delivery be improved?*

Key areas for interview schedules to cover were considered using the literature review and then developed into the questions shown below.

### **Parents**

1. Child's difficulties since ABI
2. Pre ABI functioning
3. School since ABI
4. Who supported them / how was that experience?
5. Hopes for the future

### **Children**

1. How ABI has effected them
2. Friends since ABI
3. What supported them / how was that experience?
4. Hopes for the future

### **Professionals – school based and external agency**

1. Gather some information about the status of their role e.g. job title, any specialist areas or responsibilities within the role and length of time in role.
2. Confidence.
3. Experiences of working with each other.
4. Hopes for the future.

### Points to Consider as Identified in the Literature

Boylan, Linden and Alderdice (2009) - interviews with parents prior to those with children, revealed difficulties following the ABI that researcher would have otherwise not known about.

Irwin and Johnson (2005) - closed questions to start with children; this feels easier and helps them to relax.

Carlsson, Paterson, Scott-Findlay, Ehnfors and Ehrenberg (2007); Boylan, Linden and Alderdice (2009) - fatigue may be an issue for children during an interviewing therefore the length will need consideration.

Boylan, Linden and Alderdice (2009) - Insight of children could be effected post injury; importance of parental interview.

## Child Interview Schedule

Rapport building and some closed questions to start (e.g. good day at school?)

Topic Area	Main Question	1 <sup>st</sup> prompt
<b>The ABI</b>	I understand from your parent that you ..... is that correct?	Can you tell me about what happened?
<b>The effects of ABI</b>	How has it affected you?	Strengths? Difficulties?
<b>Pre ABI</b>	Can you tell me about what school was like for you before your accident/illness?	Work? Friends? Teachers?
<b>Post ABI</b>	Can you tell me about what school is like since your accident/illness?	Work? Friends? Teachers? If I came into school and it was the best day ever for you, what would I see you doing? If I came into school and it was the worst day ever for you, what would I see you doing?
	Since your accident/illness has anybody helped you in school?	What have they helped you with? How did they help you? Could it have been any better? How?
	What was the most difficult thing about going back to school after your ABI?	Friends?
<b>Future</b>	If you could tell people at school one thing about what it is like to have an ABI, what would you say?	
	Is there anything else you would like to tell me?	

## Parent Interview Schedule

Topic Area	Main Question	1 <sup>st</sup> prompt	2 <sup>nd</sup> prompt
<b>The ABI</b>	Tell me about what happened? <sup>2</sup>	Were there any pre-existing conditions or additional needs prior to the ABI?	Medical condition that influenced or led to ABI?  Learning, behavioural, physical, communication needs?
<b>The effects of ABI</b>	What effects has the ABI had?	On the child? On yourself/partner? On other children? On extended family? On friends?	
<b>Professionals Involved</b>	Which professionals did you come into contact with after your child's ABI?	What was their role? What was your understanding of why they were involved?	
<b>School Return</b>	Which professionals were involved in your child's return to school?	What was their role? What was your understanding of why they were involved? What did you think of the support those professionals offered you and your child? <sup>3</sup>	
	Was your child's teacher(s) aware of the ABI?	Who told them?	
	Do you think there is a role for educational psychologists in this area?		
<b>Future</b>	Are there any ways in which schools and other professionals (that we have discussed) could support children with ABI more effectively?		
	Is there anything else that you would like to add?		

<sup>2</sup> After piloting, this question was used instead of: "What are your child's strengths?"

<sup>3</sup> After piloting, this question was used instead of: "What was good about the support that you and your child received after ABI?"



## School and External Agency Professional Interview Schedule

Topic Area	Main Question	1 <sup>st</sup> prompt	2 <sup>nd</sup> prompt
<b>Role Description</b>	How would you describe your role in supporting children who have acquired brain injury (ABI)?	How are you involved once the child returns to school?	
<b>Working with Others</b>	Who have you worked most with when supporting children with ABI?	Children and young people with ABI? Parents/carers of children with ABI? Teachers of children with ABI? Other professionals from external agencies?	
	In what ways have you worked with other professionals?	Face-to-face meeting? Correspondence? Long-term liaison?	
	What are your experiences of working with other agencies to support children with ABI?	Positive, negative? What would have made it better? Ask about specific professionals if not mentioned (e.g. educational psychologist).	Do you think there is a role for educational psychologists in this area?
<b>Feelings of Competence</b>	On a scale of 1-10 how confident do you feel in being able to meet the needs of children with ABI compared to other children? <sup>4</sup>	What would one step up on the scale look like?	
	What would be helpful to you as a professional in supporting children with ABI?		
	What have the challenges been in supporting child(ren) with ABI?		
<b>Future</b>	Are there any ways in which schools and other professionals (that we have discussed) could support children with ABI more effectively?		
	Is there anything else that you would like to add?		

<sup>4</sup> After piloting, this question was used instead of, "How capable do you feel about supporting a child with ABI and their parents?"

## Appendix G: Example Interview Transcripts and Coding

Interview with Parent	
I: Ok, so if we can try and think about the professionals in a bit more detail, we've talked about educational psychologists a bit already and if we think about not the one you paid for, the other one that was available from the local authority, how would you describe your experience of having that person involved overall in terms of positive, negative?	
P: How honest do you want me to be?	
I: Totally honest, as honest as you feel you can be.	
P: (chuckles) right ok.	
P: They were about as much use as a chocolate teapot – I: ok -he wasn't interested, I had basically their own family history, I knew, I heard all about their children and university and who was doing what where and what have you which was, which you know which, is nice for, for chit chat sort of thing but then that was as far as the appointment went, they wasn't interested in Owen, they didn't interview him, they didn't even know what he looked like - I: ok – and their, their whole take on it was I suggest that you give him IQ tablets – I: yeah – what the bloody hell are IQ tablets? – I: yeah - So I went off found some, I thought ok if that's what they say, it was almost like they were a drug rep, you know, so I went off bought some IQ tablets, made no sodding difference whatsoever – I: no – apart from costing me 50 odd pound – I: yeah, yeah – and I thought well ok.	<p>Negative experience of external agency</p> <p>Negative experience of external agency</p>
I: Ok, so how would you have liked to have done that differently, if you could go back in time now?	
P: If I, right, what I think they should've done, I think they should've interviewed me and got the inside skinny on what Owen was like – I: yeah - at home – I: yeah – then I think they should've interviewed the teacher or whoever, and also there was a classroom assistant that did a lot of work with Owen - I: ok -and they should've spoken to her – I: yeah – because she knew him better than anybody, and she worked really, really hard and she, she knew all the bits that he was struggling with and, and she was saying that every time she erm, taught Owen something, if she didn't go over that on the next lesson along with the next bit – I: yeah – then he'd lose it – I: yeah – so, you know and that's the sort of stuff that they should've been finding out about - I: yeah – you know all the people	<p>Future improvements – communication</p> <p>Future improvements – communication</p>

that had any dealings with Owen, they should've interviewed – I: yeah – the teacher, the classroom assistant, even the head master - I: yeah - and then of course Owen, - I: yeah - they certainly should have met Owen , I mean how can you make an assessment on a child if you've never seen them – I: yeah, ok – I think they should've been sacked for it quite honestly.	
I: So overall, is it right in saying that it was a negative experience for you?	
P: Yeah, I'd say so, - I: yeah - and I didn't realise quite how negative it was until I found out the next morning that they didn't actually see anybody else after me - I: ok – and that's, that's what really made me, I mean I was a little bit irritated about it coz I thought well you didn't really ask me anything as such, I mean we, we sort of covered a few basics, but they wasn't terribly interested, and I would have loved to have known what their notes had said, - I: yeah - whether they'd taken any notice of anything I'd said at all – I: yeah, ok – and maybe, maybe it's because of them that the statement never went any further coz it just wasn't taken, coz the whole alarm bell system just didn't work – I: yeah – because if they thought oh well his biggest issue is that he needs an omega 3 – I: yeah - then no one's gonna take any blimmin notice coz if, if it, if it all sort of comes back to them and then it's their job to say right yeah ok this kid needs looking at or you know, even if, even if they felt Owen was absolutely 100% fine and, and no problems at all, they should've asked why, why the rest of us are having a problem – I: yeah, ok – and they didn't.	<p>Negative experience of external agency</p> <p>Feelings of frustration / not feeling listened to</p> <p>Future improvement – communication</p>
I: Ok, thank you. Could you maybe kind of think about some qualities that you would like to see in an educational psychologist, erm, to be able to support children like Owen and parents as well, what sort of things?	
P: Erm, what skills do you need, well I think it helps if you, if you have a good relationship with children coz it's, it's not gonna go terribly well if you haven't – I: yeah – you know, to be able to get down and, not scrabble around the floor, but you know sit, sit down it hem and have a chat and be on their level a bit more- I: yeah – and just to talk to people, if you haven't got good communication skills it's not gonna work because it's not all about pen and paper.	<p>Hopes for the future – qualities of people</p> <p>Future improvements – skills needed</p>

Interview Child	
I: Ok thank you. I'm just interested in how you experienced school before your um brain injury er could you maybe tell me a bit about your school experience before the illness?	
<p>P: (chuckled) I was that really annoying kid who didn't do any work and good grades (laughter) - I: ok -I was that kind of person and they really annoy me now but um like I never read a book and my reading levels were and um yeah and I was I would just do the amount to get through and just do enough to get by and always did quite well and like at primary school and things and then which would really annoy my Mum coz she'd be like you need to you need to just do a bit more and then I had to (laughter) - I: yeah yeah - and it was like oh coz I have to like it's an effort just to kind of be in school and when you do so much just to to get in when you're here you kind of think well I'm gonna do the best I can just coz in comparison it's not that much more effort but before I was I was not which is I think if I'd have carried on until doing that till my GCSEs I wouldn't have done very well at my GCSEs so then it's like oh well maybe being ill was a good thing because and it like when you tell people that you've got a brain injury obviously they fr-freak out and you explain oh like my brain stops working and then I forget things and then and they're like oh and then I'm like actually in a way it was a really good thing and it's kind of pushed me to become a better person which is really hard to explain to people that actually this really horrible thing has actually been really good at the same time and kind of balancing that has been interesting but no I I school was just kind of something you did and I did well luckily without really having to do anything.</p>	<p>School after ABI</p> <p>Experience of ABI</p> <p>Experience of ABI – other people's reactions</p> <p>Acceptance and acknowledgement</p> <p>School after ABI</p>
I: Yeah ok what about relationships with people in school when you were younger like your teachers or friends?	
<p>P: Er (pause) oh god that's people, I'm not good at people erm. I don't really know, I think teachers (p) well I I'm a middle child so most of the teachers had already taught my older sister - I: ok - so there's that -I: yeah - kind of expectation but I think because I was quite nerdy and I think I was just and I was really quiet as well so I think they just kind of I guess left me to kind of get on with it and -I: yeah - you know I wasn't being outlandish and getting loads of attention so I didn't I don't think I really showed up on their radar very much until we did a test and I did quite good. Um, friends I came, I it's kind of</p>	<p>School after ABI</p>

<p>awkward I I had a friend from nursery who we came here with but we've always had quite a difficult relationship – I: yeah – and we've basically had a massive falling out and she's not spoken to me in 5 months – I: ok – but and she was the only friend that I had coming here erm from primary school erm (p) I don't know I guess I didn't really make that many connections with people coz I I'm really introverted and I don't mind being on my own. So I and then what was weird was I got ill and obviously this friend had to go off and make other friends and then so then I came back in after three months and people didn't really know who I was but suddenly she had all these friends and then I had all these friends which was weird – I: yeah - um and you I guess you kind of make connections with similar people you know like coz my friend's it's really weird coz I got ill and have a brain injury, one of my friend's Mum died of cancer when we when she was really young – I: ok -, one of my friends sister died – I: right - so we've all had kind of really bad things happen to us but we're really good friends because we all had to kind of grow up and realise that life's not always that fair but actually you can really enjoy it so I think that's we're all really kind of close now which is great but um I don't know I don't really remember before which is annoying (chuckles)</p>	<p>Peer relationships after ABI</p> <p>Peer relationships after ABI</p> <p>Acceptance and acknowledgement</p>
<p>I: No that's fine; you've said some really interesting stuff there erm and you've talked a little bit about friends since your illness coming back to school can you tell me a bit more about what school was like after you came back, how was it terms of erm the people and..?</p>	
<p>P: Erm, well everybody kind of, coz it was Jan-January of year 7 that I went so people didn't really know who I was so it was kind of like being the new girl but it wasn't because I'd been here before coz I'd been here before and all the teachers kind of knew me – I: yeah – but it was it was weird kind of integrating in the class and then because I was missing so much school and I've always missed so much school people, people would make comments about it um because, I guess because you know I'd miss one day a week it wasn't like I would have lots of time off like when I was first ill – I: yeah – I was really ill so I lots of time off – I: yeah – it was just like every week missing bits so it was kind of like you you're not really taking this very seriously or it's just you know you're just mitching or whatever – I: yeah - but and at a point when I didn't really understand what was going on it was difficult and then on top of that getting good</p>	<p>School after ABI</p> <p>Experience of ABI</p> <p>Experience of ABI / misunderstandings from peers</p>

<p>grades and stuff I was you know the boffin and the nerd but I wasn't here – I: yeah – so how did that work and everyone would kind of question me about what was going on and I didn't really understand um and then I think I stopped caring what people thought which was the best thing that ever happened – I: yeah – and um and I got a bit more outspoken, a bit more opinionated and a bit more sarcastic and people I think forgot and they kind of just found me a bit funny and they kind of stopped caring about the fact that I wasn't here and then when I was able to explain they were kind of like oh ok – I: yeah - but um so most of my class were fine um but school's (P) sometimes you get a teacher who freaks out because I'm not in school which is the worst thing because deep down I know that I'm gonna be ok like if I miss something I will catch up – I: yeah – and I'm not gonna let it go because then I just have to catch up more and more and more and I know that but when the teacher starts freaking out it's like I kind of lose that assurance – I: yeah – um but that's the only problem with I mean school, I'm really lucky that I'm at school I think because they are so willing to listen actually at the end, before I started my GCSEs on the training day, you know teachers have training days, erm my Mr X who is now my form tutor who was my history teacher at the time organised with my head of year for me to come in and do a talk about brain injury – I: right ok – which was odd for them to get a student to come and talk and it was really weird coz it was like in our school hall and usually all the kids are sat down and the teachers stood at the front and then all the teachers were sat down and I was stood at the front it was very weird but and I just like talked about my injury and they were all like, especially the ones that had taught me for the last couple of years and then they were like oh right that's why she's not been in um and then from then on they really took that on board and were like um when new teachers got me in the lesson they were like ok well what do we need to do – I: yeah - and it's like you just need to be around for when I miss school for me to come and catch up and everyone's been really approachable which has been great - I: yeah – um I think because they were so willing to listen and um you know like coz I missed three months of school but there was no talk ever of me - coz I was in top set of – of me dropping down a set or re-doing that year that was never mentioned because I think that enough kind of faith in me to kind of let me keep going which has</p>	<p>Experience of ABI over time</p> <p>Negative experience of school staff</p> <p>Positive experience of school</p> <p>School after ABI – link to one teacher and positive experience</p> <p>Positive experience of school staff</p> <p>Valued approaches</p> <p>Positive qualities of school staff</p>
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<p>been great – I: yeah – and most of the teachers kind of were like well you know your injury better than I could so if you need help which has been great coz it's like from the age of 14 and I'm like all you know missing deadlines that can't be helped they've trusted me enough to go well usually you're quite good so if you you're struggling we'll give you some leeway and things they've not been so I mean they've been great really.</p>	<p>Positive experience of school staff</p>
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<p><b>Interview with Paediatrician</b></p>	
<p>I: Ok, so next I'd like to explore your experiences of working with those other people, so maybe if we start with the specialist OT, how would you describe the experience overall in terms of how it works?</p>	
<p>P: She is, she is just so good um, and she's so thorough um, and she, working with her is very positive, she picks referrals up quite quickly, she follows through quite quickly so if we make a referral, she will generally meet the family within a few weeks um, and then start the work with, get on with some of the assessments, find out what happened, get on with some of the assessments and then start some of the work with schools, fairly soon after that I would say, there have been a few occasions where things have got very delayed but in my experience that's quite unusual and once she gets into the schools and observes a child in school and does the memory um, information recall, attention sort of assessments and does the reports, things usually begin to improve for the child if they're having difficulties, I mean not all of these children have difficulties, but most of them will have some difficulties - I: yeah - um, yes I probably don't go so involved in the ones that go well if you know what I mean – I: yeah, that makes sense in a way I suppose – yes, yes.</p>	<p>Positive experience of external agency – timely involvement</p>
<p>I: So it sounds like overall that's quite a positive working relationship – P: yes it is yes – it works well?</p>	
<p>P: And she has been around for quite a long time, maybe 10 years she has been working in paediatric acquired brain injury, so all the consultants know her, we all refer to her, we all try and make sure that every child with a significant acquired brain injury is referred to her, some of the children come into casualty go straight to Frenchay if they've got cerebral bleeding and then go home from Frenchay and we can get quite annoyed because we don't always get copied into the correspondence – I: ok – so, we sometimes these kids go home and we don't know they're at</p>	<p>Positive experience with external agency – established relationships</p> <p>Negative experience of external agencies – lack of communication</p>



<p>home already, we don't know the outcome necessarily – I: right, ok – um, so we have to be proactive in phoning up Frenchay and saying look copy us in on the discharge summary you've got to make sure we know when they're home so we can see them and we can involve the specialist OT – I: yeah - there are a few children where it's been really difficult where they have erm, elected to go back to Frenchay for the neuropsychiatric assessment to be um, done again in more detail, but these are usually families where there are other issues.</p>	
<p>I: Have you had much um, dealings with secondary schools then?</p>	
<p>P: Yes also, again I think they're not, they don't do too badly, they are more likely to say that a child with disruptive behaviour is naughty erm, but equally they have to make sure that the bulk of the children can learn and there have to be sanctions for children who, whose behaviour is outside acceptable norms, so they can't, for whatever the reason they can't have children kicking teachers, spitting, swearing in class, assaulting other children there have to be sanctions – I: yeah – when those things happen. I think the school which is the least tolerant, probably is X which probably fits, um, the schools all struggles I think, secondary schools all struggle a bit, but some of the special needs teams are very good, but I don't, yeah some of them are not as good – I: ok - but they have SENCOs, I think the difficulty in secondary schools is that they don't assign one person to be the LSA for an individual child, so they move from class to class and there'll be a different TA in each class and it can be difficult ensuring that the child develops a relationship with all the different TAs they come into contact with, so sometimes the children with additional needs get lost, despite the fact they've got statements within a secondary school environment.</p>	<p>Negative experience of school staff – lack of knowledge of ABI</p> <p>Negative experience of school staff</p> <p>Challenges of secondary school</p>
<p>I: And that they have knowledge about those particular needs – P: yeah – and how to work with them – P: yes – I suppose?</p>	
<p>I: I want to ask specifically about educational psychologists, you haven't mentioned them in terms of children with ABI but do you think there's a role for them in this area?</p>	
<p>P: Absolutely, I think educational psychologists are a hugely valuable resource, there are not anything like enough them and I would like to see educational psychologists involved much earlier really, I think the thresholds for involving educational psychology are too high and that probably reflects the fact that um, you are a relatively, I suppose in terms of education,</p>	<p>A role for EPs</p> <p>Restricted services</p> <p>Difficulty accessing EPs</p>



<p>you're relatively expensive professional team and um, local authorities have tried to reduce the cost which to me is counter-productive coz a lot of these children end up struggling for a long time and actually it's very helpful to have an assessment of their behaviour, their cognitive skills, their emotional functioning and there's work you can do to support schools around children who are struggling in a lot of areas, not just with acquired brain injury. So I always think the involvement of educational psychologists is hugely helpful and where I've been to CAF meetings where educational psychologists have been present it's been really good.</p>	<p>Positive experience of external agency – EP involvement helpful</p>
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Interview with Secondary SENCO	
<p>I: What have the challenges been in supporting a child with acquired brain injury, if any?</p>	
<p>P: Erm (p) I think it is that awareness of what is, what behaviour is linked to the brain injury and what behaviour is about choice and personality – I: yeah - and not, and making staff really aware that this brain injury that this child had does really affect his impulses, he's very impulsive, erm, he does have difficulty remembering things um, there is a lot, there's a lot of behaviour that comes with that erm, and it's not just him being naughty or forgetting to do his homework – I: yeah – erm, and just raising people's understanding and then my job in particular where you think you've done that and then you know, a couple of months later, people have either forgotten or he's moved sets so there's a different maths teacher or, or whatever – I: yeah – it's just really difficult to keep, keep on top of that um, and I think that is a challenge definitely – I: ok – I think in a smaller school or a primary school perhaps you wouldn't have that challenge because it would be much easier to be more consistent with the members of staff that deal with that student.</p>	<p>Challenges in supporting ABI – awareness</p> <p>Unique challenges of ABI – impact on child</p> <p>Challenges in supporting ABI – secondary especially</p>
<p>I: Yeah ok. Do you think there are any ways in which schools and the other professionals that we've discussed, so specialist OT, could support children with ABI more effectively?</p>	
<p>P: Um (pause) I don't know, I guess again it comes down to that commun...that communication and I think it's, oh might be a bit controversial, but I think it's always difficult when it, when there's that cross over between health and education that communication is not always clear, it's not always, we don't always get the information from hospital</p>	<p>Challenges in supporting ABI – communication</p> <p>Negative experience of external agency / hope for the future</p>

<p>appointments and things like that and vice versa - I: ok - so I think being more transparent and open between the two profession, you know the two groups of professionals I think would make things a lot easier.</p>	
<p>I: Yeah, ok. Has that come up then as in this child has had hospital appointments and you necessarily haven't heard about them?</p>	
<p>P: Yeah and things like that you know, and things with the paediatrician and those sorts of things - I: yeah - that is difficult not just with this case but you know in general - I: yeah - is something that is difficult.</p>	Negative experience of external agency
<p>I: Ok. How would you like to see it work in a better way, how could that information exchange happen do you think?</p>	
<p>P: It's better communication but because the information is sensitive, I don't know if you could do that you know, electronically or whether it would have to be like a case conference type meeting - I: yeah - where people discuss individuals - I: yeah - but in my role, the letters from the paediatricians, it's always the same few, so even if we met you know, a couple of times a year and did a case conference with, with educational psychologists there, them and us, just to share that information - I: yeah - erm, and, I don't maybe sort of a case conference where you look at solutions as well erm, that would be really useful - I: yeah -um, and I know that is the purpose of the CAF, I won't say any more about the CAF process coz I don't think it, it works in that way as it should - I: ok - in my experience.</p>	Hope for future service delivery - communication

## Appendix H: Codes, Memos and Thematic Maps for Paper One and Paper Two

Combined Child and Parent Codes (Paper One)	
Codes	Collating Codes
Coping with Resources Available to them	Challenges
A Role for Educational Psychologists	Contextual Information
Professionals Involved in School Return	
Specialist OT Home Working	
Specialist OT School Working	
Dilemma in feelings	Emotional Impact
Experience of stress	
Feelings of Fear	
Feelings Of Frustration	
Feelings of Isolation	
Grief	
On-going Memories of Incident	Impact of ABI
Absence from School	
Coping with Changes	
Effects of ABI	
Effects on the Family	
Emerging Effects of ABI Over Time	
Uncertainty About Diagnosis of ABI	
Lack of knowledge about ABI	Knowledge of ABI
Misunderstanding effects of ABI	
Acceptance or acknowledgement of ABI	Lived experiences - child
Different Experience of Incident Compared to Others	
Experience of Living with ABI	
Peer Relationships After ABI	
School After ABI	
School Before ABI	
Positive Experience of External Professionals	Lived experiences in terms of positive support received – child and parent
Positive Experience of School Staff	
Positive Qualities of External Agency Staff	
Positive Qualities of School Staff	
Negative Experience of External Agency Professionals	Negative lived experiences
Negative Experience of School Staff	
Valued Approaches	Positive experiences
Hopes for the Future	The future
Quality of Communication	
Transition to Adulthood	

<b>Combined School Staff and External Agency Codes (Paper Two)</b>	
<b>Codes</b>	<b>Collating Codes</b>
Challenges in Supporting Children	Challenges
Difficulty Accessing Services	
Funding Restrictions	
Recognition of Children's Needs	
Restricted Services	
Safeguarding Issues	
Secondary School More Challenging	
Feels Confident	
Lacking Confidence	Confidence
Unique Challenges of ABI	Contextual Information
Supporting the Family	
Works Directly with Children	
Working with Schools	EP Involvement
A Role for EPs	
Questioning Role of EP	
Usefulness of Information From EPs	How professionals work
Advocate for Children	
Close Link With Parents	
Delivers Training to School Staff	
Establishing Relationships	
Facilitates Multi-Agency Work in NHS	
Involved in Return to School	
Liaise with School Staff	
Sees Children and Family as One Unit	
Specialist Interest in ABI	
Supervision for Professionals	Knowledge of ABI
Families and Schools do Long-Term Rehab	
Highlighting ABI as Need	
Lack of Knowledge About ABI	
Understanding Effects of ABI	Negative experiences
Disappointment	
Feelings of Frustration	
Gap in Service	
Negative Experience of External Agency Professionals	
Negative Experience of School Staff	Positive experiences
Flexibility in Service Delivery	
Positive Experience of Charity	
Positive Experience of External Agency Professionals	
Positive Experience of School Staff	
Positive Qualities of External Agency Professionals	
Positive Qualities of School Staff	
School Staff Willing to Learn	

Clarity Needed on Statistics	The future
Hopes for Future Service Delivery	
Hopes for Future Ways of Working and Qualities	
Identifies a Need for Psychological Input	
Importance of Establishing Relationships	
Importance of Joint-Working	
Importance of Parents Having Knowledge	
Need for Long-Term Support	
Supporting Children to Recognise Their Needs	

## Child Memo

Five out of six children reported school as a positive experience. The sixth one reported having a positive experience of PRU but not school. All children talked about school work - some found it easier than others to catch up but it was acknowledged by all that there was catching up to be done. Linked to this, tiredness was regularly raised as an issue experienced by young people and influenced their ability to get themselves to school in the morning, let alone catch up with work.

Self-identity was discussed by the older children in particular; the coming together of the 'old self' and the self now with an ABI. Largely positive experiences with peers was reported by all children, especially with people they called 'friends' prior to their injury. Some children talked about there being some lack of understanding amongst peers and felt they had been questioned about it and the lasting impact.

The specialist OT was talked about by all children and described positively.

Children just want people to get to know them. They expressed the desire to be given a level of independence but to have people to rely on who show them unconditional regard, listen in a non-judgemental way and understand their needs/difficulties in relation to ABI rather than explaining or dismissing it as something else.

Things that children wanted to share about ABI included: you might feel like the only one; try to incorporate the old new with the new you; it may be painful; get to know the person; just have more awareness (just know about ABI, that it is a thing and that effects can be enduring/ranging); just listen; it is good to have a safe base to go to where knowledgeable trusted adults are present.

In addition to this, an interesting consideration is that children experience the incident causing ABI differently to their parents (Beth talked about this in most detail). A lack of memories about an the ABI causing incident means that the children construe it and are attached to it in a different way to their parents who were often anxious waiting to find out if their child had survived an accident or illness. This may need consideration when supporting the young person, educating them about ABI and the impact it has on them.

### **Parent Memo**

Generally parents reported positive experiences of both school staff and external agency professional staff although where negative experiences were reported, this related to a lack of knowledge about ABI and the particular child's needs (for example, needing to leave class early). All parents valued the specialist OT and qualities such as: calming, approachable,

keeping in contact, knowledge, understanding and being non-judgemental were highlighted as important characteristics. Important qualities for professionals to have when working with young people with ABI were the ability to build relationships with children and good communication skills.

Negative experiences included:

- Lack of extended help (support only limited to a certain number of sessions).
- Unclear follow up arrangements (from a medical perspective in particular).
- Some felt that they weren't listened to (by EP).
- Some felt that the information from the EP misunderstood the child/was damning.
- EP input felt to make little difference overall.

Future

- Professionals should listen more to parents as well as the young people themselves.
- Clear guidelines for how and when children and families can get support should be available to parents.
- A key person to co-ordinate this / 'do the leg work'.
- All professionals (school based & otherwise) should learn more about ABI in general, how it impacts learning and the appropriate strategies to support a child.
- Better information sharing within schools so as all staff know about a child's ABI.
- Information sharing with extended family and peers as well as other parents to improve general awareness of ABI.
- Better information about transition to adults services/support post 18.

Four out of five parents felt they had an understanding of the roles of various professionals involved in their child's care and education. One parent felt a specialist ABI EP would be of benefit - others felt unable to comment specifically on EPs because either they did not know

what the role entailed and/or felt the EP had made no difference when they had been involved.

### **School Staff Memo**

In terms of a role for EPs, there were mixed views. Some participants (two) were unsure as to whether EPs were needed at all for these children and one of these felt that recommendations made by an EP are not always clear in terms of existing school resources. The other participants (five) felt strongly that there was a role for EPs and would like to see them more often in schools. A couple of participants mentioned finding it difficult to access EPs and felt that there was too much paperwork between them and the service - they would prefer to liaise directly with EPs rather than filling in forms. In terms of challenges, school staff felt that knowing what behaviour is caused by ABI, along with the invisible and potential changing of needs is difficult for school staff to understand. Emotions were raised as a challenge in terms of supporting the emotional needs of children after they have seemingly 'recovered' as well as on-going anxiety of parents. All participants described positive experiences of being supported by external agencies apart from one participant who found it difficult to work with a health colleague as she felt that alternative viewpoints (from the school context) were ignored. Experiences with fellow school staff were generally positive although the on-going need for reminding staff about a child's needs/unique factors in ABI was raised. Having colleagues to share concerns with was a theme in terms of being supportive to each other in a school environment. In terms of future practice, the following suggestions were made: the need for parents to be aware of ABI, its causes and on-going effects; the importance of having relationships with colleagues with a shared and mutual



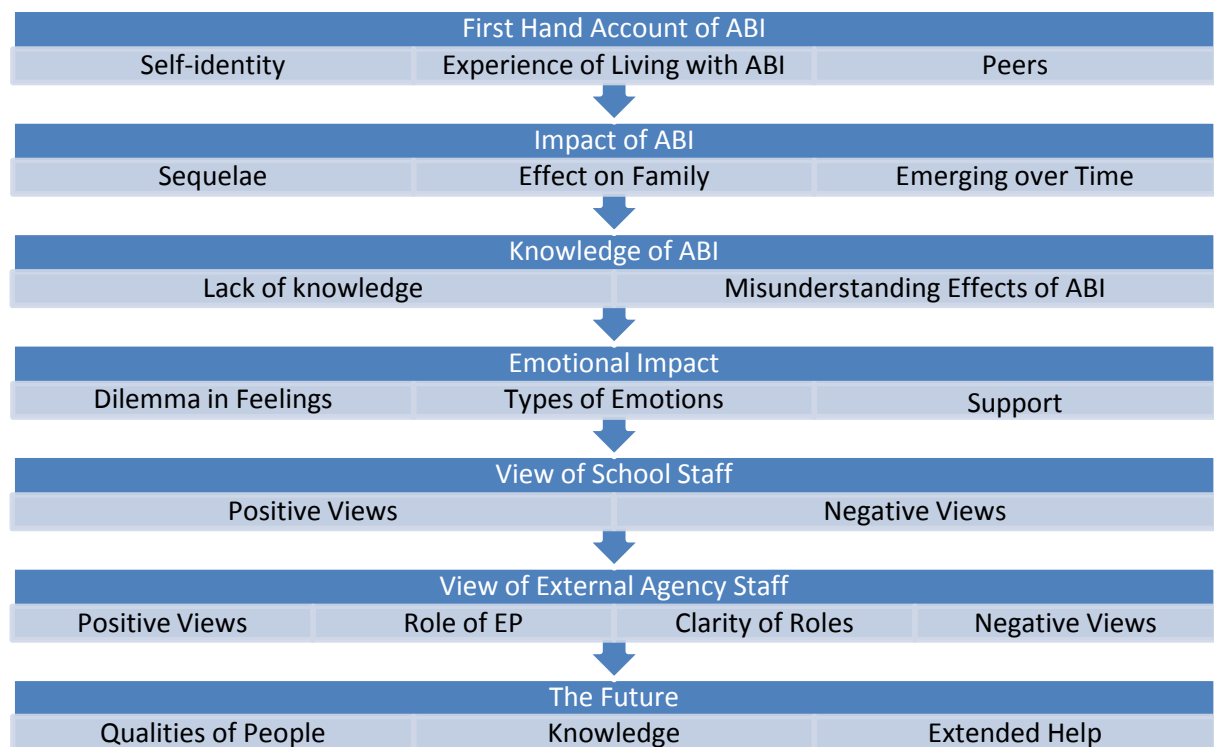
respect; more training and awareness raising in practical ways with a general ABI focuses and information specific to individual children (which could be in the form of an information pack); a bank of resources to go to as well as a 'who's who' guide for the local area; shared dialogue with parents and professionals at the same time; and stronger links with health colleagues in the form of regular review meetings about these children.

### **External Agency Professionals Memo**

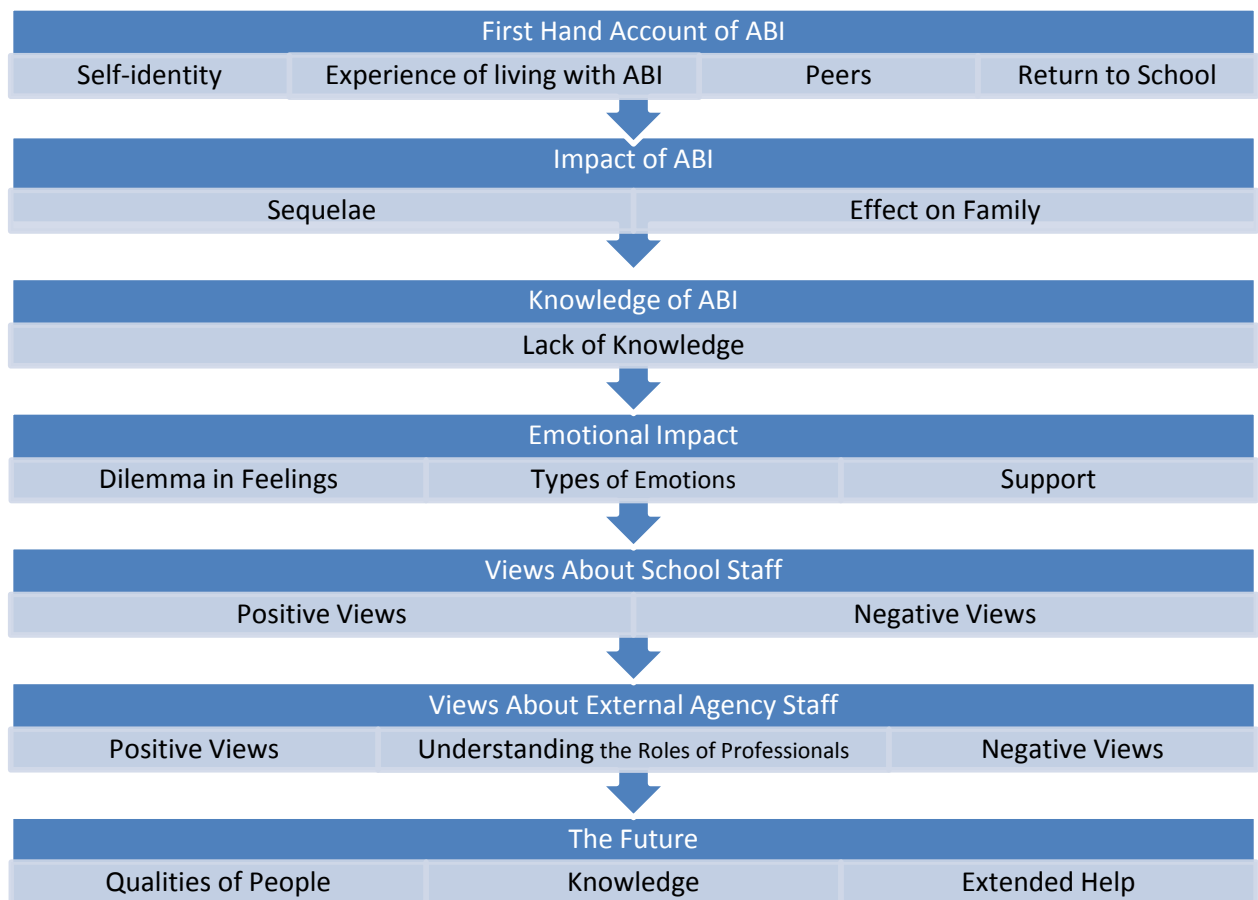
All participants talked about the need to raise awareness amongst a variety of stakeholders (teachers, each other and others such as the Police and parents), this would include more training and information that professionals could use out in the field as well as more joint working between professionals. This also included the need to promote vigilance amongst parents in relation to on-going/emerging effects of ABI as well as 'things' that may cause it in the first place. The need for emotional support for parents and children was discussed and fits with the 'emotional impact' theme in paper one. The challenges reported by this group included: knowing where the effects of ABI begin and end (i.e. when there are other interacting factors such as home life) as well as the need to know that affects can emerge over time and otherwise be unhelpfully labelled as 'naughty' for example. All participants felt that there was a role for EPs in this area although interestingly a participant doubtful about this to an extent was an EP who felt that there were other specialists who would be better placed to offer advice. In terms of working with others, experiences were largely positive, especially when timely and involving a variety of professionals. Secondary schools were highlighted as those who find it more difficult to support these children partly due to the nature of the environment (large size & often changing) although participants felt that once secondary schools know about ABI they generally do well in supporting young people.

In terms of future practice, professionals identified: a specialist team which could be virtual in nature (i.e. 'specialists' within different teams who come together when needed); strengthen links between services having opportunities for CPD and shadowing as well as just knowing who is in which team; having a key person within secondary schools to liaise with who knows the child well and is available for contact; better follow up paperwork from health sector colleagues and the possibility of 'screening questionnaires' prior to secondary entrance to identify ABI and potential difficulties associated with this.

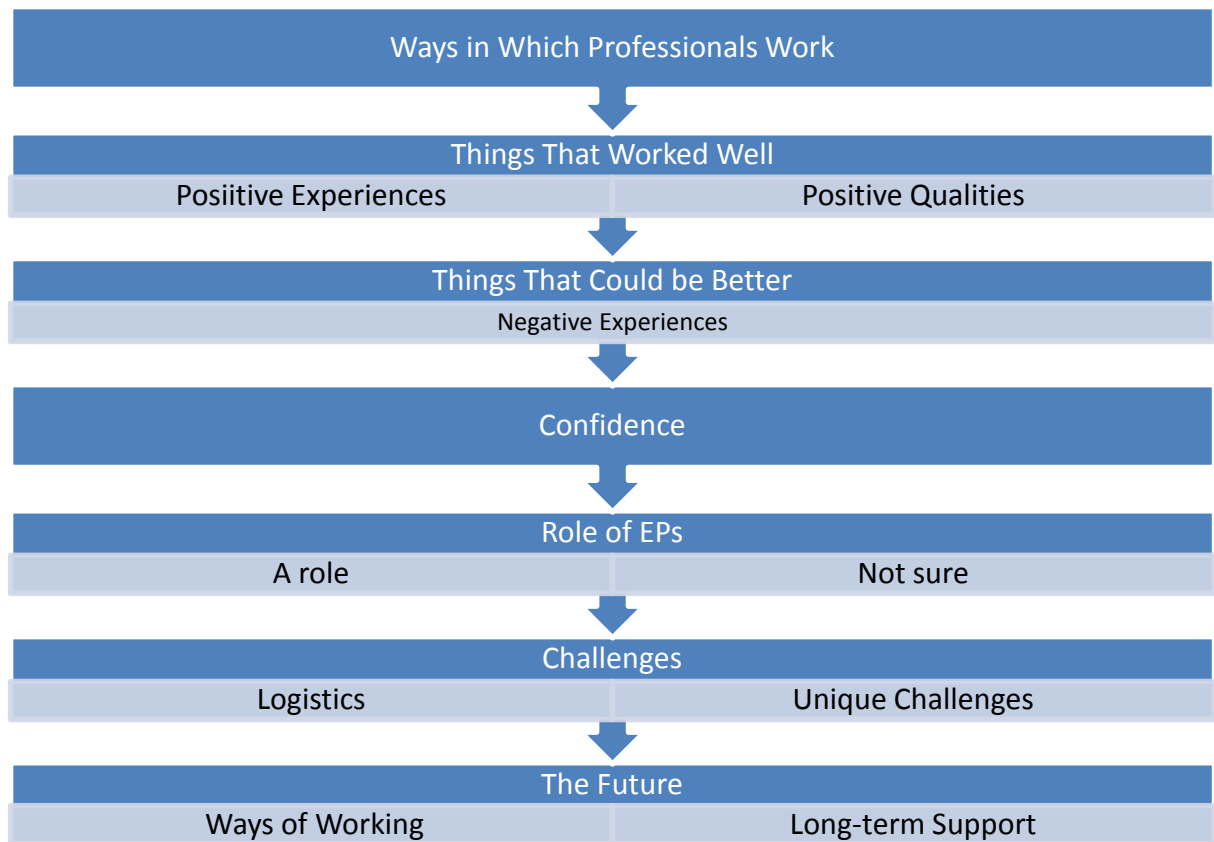
#### Initial Thematic Map for Paper One



## Final Thematic Map for Paper One



### Initial Thematic Map for Paper Two



## Final Thematic Map for Paper Two



## Appendix I: Certificate of Ethical Approval

STUDENT HIGHER-LEVEL RESEARCH DISSERTATION/THESIS	
<div><div>UNIVERSITY OF <b>EXETER</b> Graduate School of Education</div><div><b>Certificate of ethical research approval</b> DISSERTATION/THESIS</div></div>	
Your student no: 600039337	
Title of your project: Supporting Children and Young People With Acquired Brain Injury: an Exploratory Study into the Role of External Agencies.	
Brief description of your research project: The current research will refer to acquired brain injury as including any injury that has occurred to the brain after birth. A brain injury caused by external force, such as a fall or accident, is known as a traumatic brain injury whereas non-traumatic brain injury is caused by illness. Acquired brain injury amongst children has been described as a silent epidemic. The consequences of it are wide ranging and far reaching. The cognitive, behavioural, social and physical effects of a brain injury can significantly affect a child's ability to function, especially in a school environment. Existing literature suggests that school staff have a limited understanding of the long lasting, diverse effects of brain injury on school performance. There is little existing literature exploring the knowledge and experiences of professionals working with these children and the experiences of the children themselves with regard to schooling after brain injury. Therefore, the overall aim of the project is to explore the views and experiences of children and young people with acquired brain injury, their parents and the professionals who support them, with a view to developing a better understanding of how external agencies can support the education and long term rehabilitation of these children. The project will be made up of two phases which are explained below. Phase one of this research aims to explore the views of children who have acquired brain injury and their parents. It seeks to explore the support that children and parents have received in relation to schooling from professionals since the experience of acquired brain injury – things that have gone well and things that could have been better. Phase two will explore the views of professionals (school based and those from external agencies) with regard to their knowledge and experiences of children with acquired brain injury as well as which other professionals they have worked with in the process of supporting the child. Information provided by this research will be used to inform the practice of external agencies and school professionals in terms of how services are delivered to children and families with experience of acquired brain injury and what if any gaps could be addressed.	
Give details of the participants in this research (giving ages of any children and/or young people involved): Phase 1 participants: • School aged children (5-16 years) and their parents/carers. Phase 2 participants: • Professionals who work to support children with acquired brain injury. • Teachers who work in school	
Chair of the School's Ethics Committee updated: April 2011	

STUDENT HIGHER-LEVEL RESEARCH DISSERTATION/THESIS	
<div><div>UNIVERSITY OF <b>EXETER</b> Graduate School of Education</div><div><b>Certificate of ethical research approval</b> DISSERTATION/THESIS</div></div>	
To activate this certificate you need to first sign it yourself, and then have it signed by your supervisor and finally by the Chair of the School's Ethics Committee.	
For further information on ethical educational research access the guidelines on the BERA web site: <a href="http://www.bera.ac.uk/publications/guidelines">http://www.bera.ac.uk/publications/guidelines</a> and view the School's statement on the GSE student access on-line documents.	
<b>READ THIS FORM CAREFULLY AND THEN COMPLETE IT ON YOUR COMPUTER (the form will expand to contain the text you enter). DO NOT COMPLETE BY HAND</b>	
Your name: Victoria Wright	
Your student no: 600039337	
Return address for this certificate: 45 Park Road, St Marychurch, Torquay, Devon. TQ1 4QR.	
Degree/Programme of Study: Doctorate in Educational, Child and Community Psychology	
Project Supervisor(s): Andrew Richards and Margie Turbridge	
Your email address: vw224@exeter.ac.uk	
Tel: 07515559228	
I hereby certify that I will abide by the details given overleaf and that I undertake in my thesis to respect the dignity and privacy of those participating in this research.	
I confirm that if my research should change radically, I will complete a further form.	
Signed: <i>V Wright</i> date: 13.02.2012	
<b>NB</b> For Masters dissertations, which are marked blind, this first page must not be included in your work. It can be kept for your records.	
Chair of the School's Ethics Committee updated: April 2011	

- Teachers who work for the educated other than at school service (EOTAS e.g. hospital based teacher)
- Educational Psychologists
- Speech and Language Therapists
- Occupational Therapists
- Clinical Psychologists
- Physiotherapists
- School Nurses

**Give details (with special reference to any children or those with special needs) regarding the ethical issues of:**

- Headteachers and parents). Copies of your consent form(s) you will be using must accompany this document.** a blank consent form can be downloaded from the GSE student access on-line documents.

It will be essential to obtain informed consent from all of the participants to take part in interviews. Adults participants will be given an information sheet and consent form to sign. As well as informed consent from the parents for the interviews to take place with their children, I will also invite the children themselves to participate in the consent process and ensure that they are aware of what the research process will involve. Records of when, how and from whom consent was obtained, will be kept. As the young people will have experienced a brain injury, steps will be made to ensure they have a full understanding of the research and their involvement in it. Information about the study will be given to the children in a clear and understandable way and will be explained by myself. This may include giving them extra time to respond to questions, giving them a signal to use to stop if they feel tired or using pictorial supports/drawing to aid understanding and expression. Participants will also be made aware of how the research findings will be used. Informed consent will be an on-going process throughout the research with all participants as they are interviewed. Participants will also be reminded that they can withdraw consent to take part in the research process at any stage and that any data and/or paperwork related to them will be destroyed. Child and parent participants will be given a choice of where to be interviewed. If they choose to be interviewed in a school setting, I will also seek permission from the Head Teacher.

#### **b) anonymity and confidentiality**

Data will be gathered using a digital voice recorder with the permission of those people involved. Copies of the recordings and associated transcripts will be stored in a locked and secure building. Electronic information will be stored on a virus protected, secure system, accessed only through an established username and password. Once the research has been completed and approved the transcripts will be destroyed by shredding and the audio recordings will be disposed of digitally. Information will be coded to ensure anonymity, with names of people and schools being changed for the purposes of the write up. All information will be confidential, however, I will need to make it clear that any information that I feel shows a child is at risk will need to be passed onto the relevant professionals.

**Give details of the methods to be used for data collection and analysis and how you would ensure they do not cause any harm, detriment or unreasonable stress:**

Data Collection for Phase One:

- Qualitative data: Information to gather the current views and perceptions about school based support following acquired brain injury will be obtained through semi-structured interviews with parents and children. With the consent of participants, the interviews will be recorded and transcribed. I will need to approach questioning sensitively both with the children and

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updated: April 2011

their parents. It will be particularly important for me to be aware of the child's response to the process and act accordingly e.g. if the child is displaying distress or appears to be fatigued, I will need to give them the opportunity to continue or opt out.

Data Analysis for Phase One:

- The interview data will be transcribed from the audio recordings and uploaded to the computer program NVivo 9 for the identification of codes, themes and sub-themes in accordance with a thematic analysis approach. Any similarities and differences across the transcripts will be noted. The participants will receive a letter at the end of the project explaining the process and findings.

Data Collection for Phase Two:

- Qualitative data: information to determine the current views and perceptions of professionals about support for children who have acquired brain injury will be obtained through semi-structured interviews. With the consent of participants, the interviews will be recorded and transcribed.

Data Analysis for Phase Two:

- The interview data will be transcribed from the audio recordings and uploaded to the computer program NVivo 9 for the identification of codes, themes and sub-themes in accordance with a thematic analysis approach. Any similarities and differences across the transcripts will be noted. The participants will receive a letter at the end of the project explaining the process and findings.

Combining the Data From Phase One and Phase Two:

The data from both phases will be searched for comparing and contrasting themes so as explore which views are shared and where disagreements may exist. At this stage, I will be able to identify any examples of best practice as well as the main challenges experienced by those most closely involved in supporting children with acquired brain injury in terms of schooling specifically.

**Give details of any other ethical issues which may arise from this project (e.g. secure storage of videos/recorded interviews/photos/completed questionnaires or special arrangements made for participants with special needs etc.):**

During the data collection, data analysis and write up, all data (consent forms, audio recordings and interview transcripts) will be stored in a lockable drawer in a secure building. As discussed above, electronic information will be kept on a virus protected computer, accessible only by an existing username and password. All data will be destroyed (electronically deleted or shredded) once no longer required for the thesis process.

**Give details of any exceptional factors, which may raise ethical issues (e.g. potential political or ideological conflicts which may pose danger or harm to participants):**

This is a sensitive area of research and so it is essential that all participants are fully informed about the purposes of the research, give informed consent and understand their right to withdraw. Due to the sensitive nature of the topic, the children and parents especially may feel uncomfortable or it may

Chair of the School's Ethics Committee  
updated: April 2011

provoke feelings of distress. In this event I will not pursue any further questioning and will ensure their well-being at all times. Participants will continue only if they feel comfortable to do so (and this may be at a later date) and will be reminded that they do not have to take part in the project at all.

I am also aware that a thorough debriefing process will be necessary for all participants involved. I anticipate this to be a two-stage process. Firstly I will allow participants time to ask me questions/make comments at the end of the interview process. I will also be prepared with relevant information for participants to access further information/support/advice e.g. the 'youth zone' website of the Child Brain Injury Trust and a list of useful websites/reading for parents and professionals. Secondly, towards the end of the whole research process I will provide the participants with a summary of what I did and what I found as well as the hoped for outcomes in terms of informing understanding and practice, as mentioned above, this could be in letter format.

Finally, I think it is important for me to acknowledge that a power differential will exist between myself and the participants (especially the children and parents). My dual role as a professional Trainee Educational Psychologist and doctoral research student will need to be made clear to the participants. It will be important for me to emphasise clearly and succinctly to parents and/or professionals (parents especially) that my current role is that of researcher. I will not be assessing or 'treating' the child in question, rather I am seeking to explore current views, experiences and issues of children with acquired brain injury and the adults who support them with the aim of informing future practice.

---

***This form should now be printed out, signed by you on the first page and sent to your supervisor to sign. Your supervisor will forward this document to the School's Research Support Office for the Chair of the School's Ethics Committee to countersign. A unique approval reference will be added and this certificate will be returned to you to be included at the back of your dissertation/thesis.***

*N.B. You should not start the fieldwork part of the project until you have the signature of your supervisor*

---

**This project has been approved for the period:** 13 Feb 2012 **until:** 18 May 2013

**By** (above mentioned supervisor's signature):  **date:** 13 Feb 2012

*N.B. To Supervisor: Please ensure that ethical issues are addressed annually in your report and if any changes in the research occur a further form is completed.*

**GSE unique approval reference:** 2/12/12

**Signed:**  **date:** 21/2/2012  
Chair of the School's Ethics Committee


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This form is available from <http://education.exeter.ac.uk/students/>


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Chair of the School's Ethics Committee  
updated: April 2011





Hi! My name is Vicky  
and I am carrying out a project to find  
out what children and young people  
like YOU think about school.....



# HAVE YOUR SAY.....

I will talk to the person who  
cares for you

↓

I will then talk to you about  
school

↓


I will then talk to adults  
who work in schools

↓


I will put all the information  
together to see what is  
going well and if there is  
anything that could be  
made better to help you at  
school

I would like to find out about the school experiences of children who have  
experienced a brain injury. I would like to do this by talking to children and  
young people about how they find school, who has helped them, what is  
good and what could be better. I would record our talk to help me  
remember what we said and then I would take notes from the recording of  
our voices. I will ask you to choose a pretend name so that when I write  
about what I learned from our talk, people reading it will not know it was  
you I spoke to.

**Please contact me for any more information:**



01274 800000@baxter.ac.uk



07515559228

### ASSENT FORM FOR CHILDREN AND YOUNG PEOPLE



My name is Vicky and I would like to invite you to take part in a research project that I am doing. I am doing this project to learn more about how adults can help children and young people in school who have experienced a brain injury. I will also be talking to your mums and dads and adults who work in schools.

I will keep everything you tell me private. But if you tell me that you have feelings of hurting yourself or someone else, I will have to tell someone about that. If you tell me someone hurt you, I would have to tell someone about that too, but not the person who hurt you.

You do not have to be in the study, and you can stop if you do not want to do it, at any time.

**Child's Assent:** I have been told about the study and know why it is being done and what I will be asked to do. I also know that I do not have to do it if I do not want to. If I have questions, I can ask Vicky or \_\_\_\_\_. I can stop at any time.



YES



NO

NAME: .....

DATE: .....

My parents/guardians know that I am being asked to be in this study.

#### Contact Details

For further information about the research or your interview data, please contact Vicky Wright (Lead Researcher) on: [vw224@exeter.ac.uk](mailto:vw224@exeter.ac.uk) or 07515559228.

Supporting Children and Young People With Acquired Brain Injury: an Exploratory Study  
Into the Role of External Agencies.

**CONSENT FORM FOR CHILDREN TO PARTICIPATE**

**Details of Project**

This project aims to explore the views and experiences of children and young people with acquired brain injury, their parents and the professionals who support them, with a view to developing a better understanding of how external agencies (i.e. those outside of the immediate school context) can support the education and long term rehabilitation of these children.

**Confidentiality**

With your consent the interview will be recorded and then transcribed by me. The recordings and transcriptions will be stored securely on a password protected computer. Data from interviews may be discussed with other researchers in professional supervision meetings although this will be done on an anonymous basis.

**Anonymity**

Interview data will be held and used on an anonymous basis with no mention of names (you will be asked to choose a pseudonym) but you will be referred to in terms of the group of which you are a member (child, parent or professional) in the research write up.

**Consent**

I voluntarily agree for my child to participate and for the data to be used for the purposes specified above. I understand that my child and I can withdraw consent at any time by contacting the researcher.

TICK HERE: ☐

DATE: .....

Name of interviewee:..... (Parent)

Signature:.....

Email/Phone:.....

One copy of this form will be kept by the participant; a second copy will be kept by the researcher.

**Contact Details**

For further information about the research or your interview data, please contact Vicky Wright (Lead Researcher) on: [vw224@exeter.ac.uk](mailto:vw224@exeter.ac.uk) or 07515559228.

## EDUCATION RESEARCH OPPORTUNITY: HAVE YOUR SAY...

### Supporting Children and Young People With Acquired Brain Injury: an Exploratory Study Into the Role of External Agencies.

This is a two phase project aimed at developing understanding of children's experience of school following an acquired brain injury. An acquired brain injury is described as any injury that happens to the brain after birth and a period of typical development. It can be caused by a fall or accident (traumatic) or by an illness or infection (non-traumatic).

Phase one aims to seek the views of children and their parents in terms of their schooling experience since their brain injury and the support they received from external agencies.

Phase two aims to seek the views of professionals in school and those who work with schools as part of an external agency in terms of their knowledge and understanding of working with children who have acquired brain injury and their experience of working with other professionals in supporting these children.

Participant views will be collected through interviews with the lead researcher. Interviews will be recorded and then transcribed. Themes in the data will then be identified.

The results of the project will be used to identify gaps in knowledge and to inform professional practice at a school and external agency level.



For any further information  
please contact Vicky Wright  
(Lead Researcher) on:  
[vw224@exeter.ac.uk](mailto:vw224@exeter.ac.uk)

or

07515559228

#### KEY INFORMATION:

- Children and young people with acquired brain injury
- Two phase project
- Phase one – children and parents
- Phase two – professionals
- Interviews
- Identify key themes
- Inform professional practice

Supporting Children and Young People With Acquired Brain Injury: an Exploratory Study  
Into the Role of External Agencies.

**CONSENT FORM FOR PARENTS AND PROFESSIONALS**

**Details of Project**

This project aims to explore the views and experiences of children and young people with acquired brain injury, their parents and the professionals who support them, with a view to developing a better understanding of how external agencies (i.e. those outside of the immediate school context) can support the education and long term rehabilitation of these children.

**Confidentiality**

With your consent the interview will be recorded and then transcribed by me. The recordings and transcriptions will be stored securely on a password protected computer. Data from interviews may be discussed with other researchers in professional supervision meetings (although this will be on an anonymous basis).

**Anonymity**

Interview data will be held and used on an anonymous basis with no mention of your name (you will be asked to choose a pseudonym) but you will be referred to in terms of the group of which you are a member (child, parent or professional) in the research write up.

**Consent**

I voluntarily agree to participate and for the data to be used for the purposes specified above. I understand that I can withdraw consent at any time by contacting the researcher.

TICK HERE: ☐

DATE: .....

Name of interviewee:..... (Parent / Professional\*)

Signature:.....

Email/Phone:.....

One copy of this form will be kept by the participant; a second copy will be kept by the researcher.

**Contact Details**

For further information about the research or your interview data, please contact Vicky Wright (Lead Researcher) on: [vw224@exeter.ac.uk](mailto:vw224@exeter.ac.uk) or 07515559228.

\*Delete as appropriate

## **Appendix K: Additional Quotes for Themes Outlined in Papers One and Two**

### **Paper One**

#### Research Questions One and Two

Question one: How does a child who has experienced ABI describe their experiences of school since the injury?

Question two: What are the views of parents of children with ABI with regard to their child's schooling experience since the injury?

### **Theme One: First Hand Account of ABI**

#### **Self Identity**

"It was more to start with just to accept that I'd been ill and then slowly it was like ok, well this is happening to me now and I have this injury and what does this mean?" (Beth, Child)

#### **Experience of Living with ABI**

"I think catching up with the work and getting there, like waking up and getting there and getting back." (Mike Child)

"I don't remember being ill so I don't really have much of a connection to it so it was kind of like a blip for me and then for my family it was really horrible so they wanted to blank it out." (Beth Child)

### **Theme Two: Impact of ABI**

#### **Effect on Family**

"She's sometimes been quite um, a bit of classic sibling jealousy about Jack, he's two years younger and Lizzie very much was the centre of attention before he was born." (Michelle Parent)

“Of course the other two were like, where’s our brother – I: yeah - we want our other brother back, you know, what the hell’s wrong with him.” (Belinda Parent)

### **Theme Three: Knowledge of ABI**

#### **Lack of Knowledge**

“I get the feeling that they, they’re geared up to dealing with disruptive children or maybe children who do have a diagnosis you know of um, an autistic spectrum disorder or ADHD or another recognised learning disability but this is something that they really don’t know, really how best to do deal with so I think they do need that expertise.” (Michelle Parent)

“I don’t think the statement’s as detailed (p) you know, it just says learning difficulties, big deal, I mean that could mean a million and one different things.” (Karen Parent)

“It’s a fight to get people to understand that he’s just not being naughty and, and he’s not um, oh its hormones, no it’s not bloody hormones because this started the day he came home.” (Belinda Parent)

### **Theme Four: Emotional Impact**

#### **Types of Emotion**

“The isolation of, of having three normal children and then one that was tired and bleeding all the time and had headaches all the time and disruptive behaviour and couldn’t remember to get dressed.” (Belinda Parent)

“To have the statement and ... then you read it and it’s like ok it sounds like you’re going to get help and then it’s not the help that you think you’re going to get.” (Belinda Parent)

## **Theme Five: Views About School Staff**

### **Positive Views**

“She’s a teacher but she was also like a mother figure, she helped me through a lot, if I couldn’t talk to my Mum about silly things, I’d always talk to her and she’d always help me through everything.” (Cassie Child)

“I did feel that the Head Teacher was here for me and they were lovely, she was lovely, she used to phone me in Bristol to find out how he was.” (Janice Parent)

## **Theme Seven: The Future**

### **Knowledge**

“I get that it’s a really varied thing and it’s a really wide ranging thing – I: yeah – and every kid’s different anyway so you do have to take them on an individual basis but just knowing that brain injury is actually a thing.” (Beth Child)

“You know for parents to come in you know for awareness you know like they do for drug awareness ... you know put speaker explaining, someone like the specialist OT, yourself, explaining.” (Susan Parent)



## Paper Two

**Research Question One: In what ways do professionals support children, young people and their parents following ABI?**

### **Theme One: The Ways in Which Professionals Work**

“Thankfully with things like emails, you’ve got a, it’s more, you can actually, you know perhaps ask more because by sending off an email they can respond to you in their time rather than actually having to be pulled away from a class and answer a phone – I: yeah – so I think that’s, that’s got its benefits.” (Emily EOTAS)

**Research Question Two: What are the views and experiences of professionals working with children who have experienced ABI?**

### **Theme Two: Aspects That Worked Well**

One participant also talked about her positive experience of a charity and training she had completed with them and the usefulness of this.

“I did find it extraordinarily useful (p) erm and I was able to come back and implement some of the ideas.” (Emma Secondary TA on training)

“She’s really clear erm, about listening to some of the issues that we’ve had with the child and explaining how the injury, the brain injury would have an impact on that um, but also, erm, she seems to understand schools, so the advice that she gives is really practical.” (Jane Secondary SENCO on the Specialist OT)

“Over the last decade or two since I’ve been working as a consultant, schools have improved dramatically in how they manage children with additional needs, the inclusion agenda is fully embedded now.” (Nicola Paediatrician)

“Sharing of information erm, is very important, we tend to get together in small groups to share any important information like this.” (Stephanie Primary SENCO)

### Theme Three: Aspects That Could be Better

“I always like it if you do get a feedback from the clinical team that might be...but you never do, you never do.” (Miranda EP)

### Theme Four: Confidence

#### Feeling Confident

“I know how to refer and I know about the multi-agency kind of environment they’ll be in, but I’m not skilled or trained to do the detailed assessments of memory, language, fatigue, mood – I: ok – dealing with a post-traumatic stress disorder.” (Nicola Paediatrician – shows there are some things that she is more confident about)

“I feel, (chuckles) I feel very confident for the children that come to me that have cognitive or behavioural or social needs.” (Anne Specialist OT)

#### Lacking Confidence

“I didn’t feel confident about what I was telling the school I felt that they probably would feel that I wouldn’t be equipped enough to have the key information for them.” (Miranda EP)

“I think I didn’t feel confident I think um er yeah I didn’t feel confident and I knew obviously, you know, starting with let’s talk about when child nearly died um let’s talk about when he nearly died – I: yeah – you know – I: yeah – that’s gonna be hugely opening a, a can of worms isn’t it.” (David EP)

“I did feel as a professional rather out of my depth, because I was basing it on an understanding of what I’d been told from the mum, I wasn’t privy to any medical information because the mum simply hadn’t had any medical information.” (Miranda EP)

## Theme Five: The Role of the EP

“I think it’s really important that Ed Psychs can build that relationship with the teacher and kind of get in there – I: yeah – and do that kind of education and support.” (Harriet CP)

## Theme Six: Challenges

### Logistics

“I mean for me it’s, it’s very difficult (p) yes interpreting that sometimes interpreting the significance of acquired brain injury in a child’s overall functioning, particularly if the parents tell you about a historical injury and you have no way of um, assessing the significance of it and it’s also, we’ve had one very difficult young man, he’s nearly an adult now, where there were major family issues that were close to child protection of domestic violence, maternal depression, very dysfunctional family relationships, poor nurturing and attachment”. (Nicola Paediatrician)

“I think it is that awareness of what is, what behaviour is linked to the brain injury and what behaviour is about choice and personality – I: yeah - and not, and making staff really aware that this brain injury that this child had does really affect his impulses.” (Jane Secondary SENCO)

“just raising people’s understanding and then my job in particular where you think you’ve done that and then you know, a couple of months later, people have either forgotten or he’s moved sets so there’s a different maths teacher or, or whatever – I: yeah – it’s just really difficult to keep, keep on top of that um, and I think that is a challenge definitely.” (Jane Secondary SENCO)

“I think from a teaching point of view that’s quite hard to understand, I think you do have to put on a sort of a psychological or a medical or a different sort of hat to understand that and I think as a, a normal class teacher teaching French or whatever, that’s quite hard to, to sort of understand.” (Jane Secondary SENCO)

“I think, erm, possibly understanding myself and then passing on that understanding - I: yeah – because as I say, each one is individual.” (Emma Secondary TA)

## Unique Challenges

“He also has quite a short term memory issue.” (Jane SENCO)

“I’m talking moderate and mild because they have problems with learning – I: and I guess they’re the ones in the mainstream school – yeah – I: that as you say might kind of go under the radar.” (Anne Specialist OT)

“Also the nature of brain injuries is often er presents very differently in one child compared to another child so it’s very difficult to have a rule of thumb.” (David EP)

“He has issues with um, reaching round his body, that like his arms, he finds it difficult to do things, gross motor things, - I: yeah, yeah - that lots of other people find quite simple.” (Kelly Primary Teacher)

“I was thinking oo of all the children that I’ve worked with, with brain injury, they’ve all been so different.” (Emily EOTAS)

“I think there are a lot of children out there a, quite a large number of children out there who where their acquired brain injury just isn’t um, recognised at all and I think the definition is really wide.” (Nicola Paediatrician)

“I guess just more information and knowing where to go, who do I ring – I: yeah, ok – you know, who, who’s gonna come and support with that young person. “ (Kelly Primary Teacher)

“The other thing is you know how much weight do we put on that....often we have examples of incidents and we’ve got no way of knowing what the significance of that is and whether it is an acquired brain injury.” (David EP)

“The fact that their needs change and grow all the way through. So you can’t just have your injury at 5 and have a little bit of input and that’s it.” (Anne Specialist OT)

“This particular person has become a teenager so a lot of that behaviour is sort of teenager behaviour but exaggerated or more intense or, or more spontaneous at

times or volatile I guess is a better word because of the brain injury.” (Jane Secondary SENCO)

### **Research Question Three: How could support offered by these professionals be improved upon?**

#### **Theme Seven: The Future**

##### **Ways of Working**

“I think a joint piece of work, OT and Ed Psych at that you know, joint guidelines to the staff erm would be a really helpful document to you know for us both to meet, or do our assessments, put a joint document together.” (Anne OT)

“I think it’s about putting in context and making it accessible for all erm, but for it to be really successful it would have to be a whole school input really.” (Jane SENCO on training)

“if that’s going to be successful and it’s going to be effective, people working together actually also means people having mutual professional respect for each other, so you know, there will be things that you could tell me about a child that would be helpful to me but equally there will be a whole lot I can tell you.” (Carol SENCO)

“I guess a lot of it is just raising awareness of issues involved and I guess schools I find sometimes aren’t as aware.” (Harriet CP)

“Sometimes staff come with questions erm, or they’re keen to find out more and it would be really good to signpost them to resources or even have the resources here – I: yeah – where they can take it away and read up on it themselves – I: ok erm, not just information about a particular individual but more general, definitely.” (Jane SENCO)

“Sometimes staff come with questions, or they’re keen to find out more and it would be really good to signpost them to resources or even have the resources here where they can take it away and read up on it themselves, not just information about a particular individual but more general.” (Jane SENCO)

## Appendix L: Overall Reflections on the Findings

The overall experiences of all participants in both papers of this research was more positive than I had expected they would be. Less than positive experiences were in fact more subtle and specific in terms of which areas of support and professional practice they related to. For example, some parents reported that they did not feel as involved as they would have liked to (e.g. in planning future educational experiences for their child or in contributing to a professional's assessment of their child). Given my training and experience so far in terms of EP practice, I would have expected parents to have felt involved in processes concerning their child's care and education. Their perceived lack of involvement came as a surprise to me and has helped me to reflect on the different ways other professionals and school staff may approach their work with parents. In addition to this, the role of the EP and value of this to their child and situation of the family was not unanimously agreed upon by parents. This again was a surprise to me and perhaps is indicative of the value in promoting the role of the EP and the benefits of it to parents.

It was interesting, and unexpected that based on what they said, some participants interviewed for paper two knew less about ABI than they thought they did. Therefore, despite some training and direct work experiences with a child who has an ABI, some participants need to develop their understanding of ABI as a phenomenon and its potential long-term impact. This supports the clear requirement for further training and knowledge development amongst the children's workforce. Of perhaps greater interest is that the participants interviewed for paper two had many constructive suggestions about improvements for the future in terms of professional practice and service delivery. Whilst some participants did not realise that what they said indicated less understanding than they

claimed to have, they were able to reflect on how things needed to change and be improved. The ease with which all participants in paper two discussed improvements for the future is indicative of how ABI in education is a significant issue that needs to be addressed in a dedicated and structured manner that is useful and practical to the education context. Finally, I was surprised at how the systems for recording the occurrence of an ABI and tracking the children and young people thereafter is so lacking. From my reading of the literature, this appears to be an existing issue across areas rather than an omission in the local authority focused upon in this research.

## Appendix M: Future Research

Considering this research as two papers together in relation to future directions of research in the area of childhood ABI is also important. At a broad level, through my experience of this current research and the difficulty at times to identify participants, it would be useful for future research to focus on establishing statistics relating to ABI more clearly. To develop the work here and that of the key pieces of existing research (such as Bozic & Morris, 2005; Ball & Howe, 2013), it would be beneficial to conduct related research on a larger scale. This current research and those leading already in the area have been small scale and to develop understanding of the services supporting ABI in children and young people and how these are experienced by the people using them, it would be beneficial to conduct research across a larger region or even nationally in terms of service audits or the role of EPs, for example.

Linked to this, the scope of future research could be broadened further in terms of the participants included. A wider variety of professionals than was included in this current research, as well as more representatives from each group would give scope to understanding more about how they work with young people after ABI, how services are delivered and what, if any, gaps exist. In terms of exploring the ecological system of children with ABI in more detail, the siblings and or peers of children and young people could also be included in future research.